The experiences of Omani mothers of children with Autism Spectrum Disorder: Lives and educational decisions

PhD thesis
Submitted by
Raya Suleiman Al Raesi

August 2021

To the University of Exeter as a thesis for the degree of Doctor of Philosophy in Education

This thesis is available for Library use on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

I certify that all material in this thesis which is not my own work has been identified and that any material that has previously been submitted and approved for the award of a degree by this or any other University has been acknowledged.

(Signature)
………………………………………………………………………………………

Dedication

O’ Allah! All praise and gratitude be to You.

Abstract

This research explores the experiences of Omani mothers in their lives with their children with autism spectrum disorder (ASD) and the decisions and choices they make about their education. The study is comprised of three sequential phases with three different data collection methods: the first is a story narration (written or recorded by 25 mothers); the second phase involves semi-structured interviews with 11 mothers; the third phase incorporates in-depth building-rapport days with three mothers and their children. Thematic analysis is used to try to understand and to examine the experiences of the Omani mothers of children with ASD.

The findings show that receiving a diagnosis of ASD for their children is a highly important event that results in a range of emotional responses in Omani mothers. Mothers also express different emotional responses about their children's development and about their hopes and concerns for their children's future. A number of influences seem to contribute to mothers' educational decisions and choices, for example, the child's characteristics, the family's financial position, community support (formal and informal) and previous/current school experience. Findings also suggest that limited public awareness of ASD and lack of guidance and information seem to affect these decisions and choices. The research finds that these mothers have different experiences with regards to the availability of services for children with ASD in Oman, the process of accessing them and the quality of these services, if any. Implications are discussed for supporting mothers when making choices for their children's education and ways of supporting them to achieve a more positive experience when accessing services. These include raising awareness of the public in Oman about ASD, improving the services for children with ASD and providing more information for parents.

Acknowledgements

I would like to express my deep and sincere gratitude to my supervisors, Professor Hazel Lawson and Dr. Alison Black. Their extensive knowledge and supportive approach to supervision have been of great value to me. Their understanding, encouragement, personal guidance and feedback on earlier drafts of the thesis have provided a good basis for the present work. I would like to thank them for their patience and support in my study.

I would like to thank the 25 mothers who participated in this study for their time, cooperation and willingness to share their personal experiences that helped me to complete this study.

I am also indebted to my ever-encouraging husband, Sultan, whose unconditional love and support made me decide to go on this journey in the first place. I would like to thank him for everything. Great and sincere thanks to my family for surrounding me with their care and love thought this thesis journey. Their continuous reassurance and unfailing encouragement made the completion of this research a reality. In closing, my lovely children, Mohammed, Rahaf, Rafifi, Reem and Suleiman, who were patient and understanding, to whom I must give special thanks.

Table of Contents

List of tables

List of figures

List of abbreviations

ASD	Autism Spectrum Disorder
MOE	Ministry of Education
MOH	Ministry of Health
MOSD	Ministry of Social Development

Chapter One: Setting the Scene

1.1 Introduction

This study explores the experiences of Omani mothers of children with ASD, and their lives generally, and looks specifically at their decision-making. The main aim of this introductory chapter is to set the scene of the study by narrating the researcher’s own experience with her child with ASD, which is the principal underlying motivation for the study topic. The focus of the study is then defined in detail, its importance presented, and the research questions outlined. The chapter ends with the thesis outline.

1.2 The starting point (my story as the mother of a child with Autism Spectrum Disorder (ASD)

Parents, in general, wish to have a healthy, smart child with an attractive personality. Like most mothers, I wanted my child to be born healthy, to be beautiful, and to grow as smart and intelligent as many other children. I had ambitions for him to be well educated and to have his own strong personality, to be a good speaker, to be a leader, or to learn three or four languages. The first moment I saw him, I felt that my son would be a very successful person and that he would change many aspects of our life as a family. He did, but not in the way I expected.

All those dreams have been shattered, and everything changed as my son grew older. My child was born healthy but we soon noticed that his developmental stages were totally different from other children in his age group. As an infant, he did not show interest in walking or talking, and he was late in calling us “Mama” or “Dada”. From the moment he was born, I sensed that something was not right with him. I never knew what had happened to cause his ‘problem’. People around me, at my child’s early age, were comforting me that there was nothing to worry about, and they were telling me stories of children who were late in their development but later on became as ‘normal’ as others I was also trying to convince myself that my baby was as ‘normal’ as all other children. However, my instinct as a mother told me my son had a ‘problem’, and I needed to find out about it. Although he was strong and healthy, he was deemed to have severe learning difficulties. He was unable to respond well in various situations, and his speech was often difficult to understand as he was repeating phrases in a continuous and vague way.

For the first five years, my husband and I were trying to understand our child’s ‘problem’. So, we visited many hospitals, and we met many doctors. At the beginning, different doctors used a variety of labels such as Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, and severe learning difficulties. We never knew what these meant; however, they made us feel comfortable as they were not serious issues to worry about. After a long battle with a medical diagnosis in Oman, a neurologist was able to provide us with a diagnosis for our son, and he said that our child might have something called Autism Spectrum Disorder (ASD). However, in order to be sure of this diagnosis, we needed to go to a diagnosis centre in the United Arab Emirates (specifically, the Dubai Autism Centre). At the beginning, I was not really bothered with the label because I did not know its meaning, and I had heard many doctors using many labels, so it could have been similar to the labels I had heard about previously. When I started reading about ASD on the internet, we felt devastated because I felt that it was my fault and that maybe I had done something that had affected my son’s early growth. When I experienced ASD through my son’s behaviour, I felt both that I was a bad mother as I could not parent my child well and that I was the only mother who had a child like my son.

I spent two years looking for a magic pill that would make my son better. I strongly believed that it was a disease, and I was looking for a cure. I went to many doctors and tried many things that might help. I visited many traditional healers and used many traditional medicines to help cure him of the ‘disease’. I paid a lot of money for doctors and therapists, but he was barely improving. I never stopped, and I desperately continued searching. I wanted a miracle. I wanted to wake up one day and find that my son had ‘recovered’ from ASD. However, my feelings as a mother did not stop me supporting my son. Maybe it took me a long time to accept that he would always have ASD, but I came to realise that all I could do for him was to give him the tools to manage his life the best way he could. When I reflect back, I did not treat him differently in all his growth stages, maybe because he was my first child. Having ASD would never prevent me from being his mother, loving him, and looking after him. I always tried to find ways to train and teach him, such as being independent in feeding himself, getting dressed, or going to the toilet. I struggled with him, but managed to succeed in training him to be independent in many life skills.

My husband and I aimed to find out what we could do to support our child's development and learning, and what support was available in our country for a child like him. At the beginning, we were looking for a 'label' for our child's condition. Later, we felt that a label was not important, but what was important was to support him in different stages of his education. Our first choice was to find a place for him in a private, mainstream nursery, though we knew there was a lack of support for his condition. However, we thought that staying at home without support would affect him negatively. Home schooling was not an option for me as a working mother and was not accepted in the educational system in Oman, so I did not consider it. At the age of 6, he was in a transitional stage of moving from nursery to primary school. Our choice was to enroll him, like other typically developing children, in a public mainstream school. We had always wanted him to be educated in a mainstream school. Our choice of mainstream education was made to help our son grow up in a 'normal' environment and to develop good social skills with other children, rather than the seemingly artificial world of special schools. We thought that segregation might make it difficult for him to socialise and communicate effectively. This was generally acceptable for us as parents, but the idea was rejected by teachers and the administration of the mainstream school, who refused to accept our son in their school. The school administration was not aware of the meaning of ASD, and they had no understanding of how to work with him.

As parents, we had mixed feeling between what would be good for our son. On the one hand, we wanted mainstream school to develop his social skills and other skills. However we also felt that including him in a mainstream class in a mainstream school would be a difficult environment for his development. Our choice then shifted to special classes in a mainstream school. Though it was not my preferred choice, these classes were special classes for children with developmental problems, such as those with ‘Downs syndrome’ or those with a ‘mentally retarded’ condition (as described by the school). Therefore, I fought for him to be included in these classes, and searched for information as to how to enroll him. After one year’s struggle, I was able to enroll him in these classes, and I was lucky to find a place for him. I was not sure that these classes were suitable for my son but I did not seem to have a choice, and there was no guidance from school teachers or from other professionals that could assist me. An education service was provided in these special classes, but I genuinely felt that the resources available there were inadequate. This left me with mixed feelings. I had the ‘dilemma’ of keeping him in a school with little support or taking him out of the school, with no other options available. Therefore, our choice was to keep him there, so he spent one academic year, 2009/2010, in a mainstream school.

At this stage, my husband and I prepared an educational plan to support our son’s development. The plan was to include us as parents, the school, and the community, and it was intensive. From 2010 to 2015, my son went to a special classroom in a mainstream school every morning. We also enrolled him in a special private centre for extra support, and we integrated him in the community for all social events such as weddings, Eid celebrations, birthday celebrations, and family gatherings. The teachers in the special class within the mainstream school supported him with his literacy, helping him with reading and writing. In the evening he had one hour of one-to-one speech sessions with a speech therapist. He had developed considerably, but he still needed a lot of support. I simply hoped that one day in the future, my son would be able to lead an independent life and be happy. I wanted people to accept him the way he was.

One of the motives for me to think of moving to the UK was to look for a ‘better’ place for my son and I could not do that without government funding. Thus, I applied for a PhD scholarship, and I got accepted. In September 2015, I moved to the UK for PhD studies along with my son and my family. The plan was to stay here for four years and my son would join one of the special schools. Since then, I have found that the services, the schools and the teachers working with Mohammed, my son, have met my expectations. This is our final year in the UK and we will then move back to Oman. So now, I need to think of a new plan for my son as he will be 17 soon. I have been gathering information from different people and different organisations, but I do not know what will happen next. What I know now is that I will try to do my best for my son and my family.

I understand that my story as the mother of a child with ASD is one story amongst similar stories of many other mothers. I used my parental lens here to think about the choices available to mothers as to how to educate their children with ASD and their lives with them. If children with ASD are likely to be rejected from schools because of their developmental problems, what alternative choices do mothers have in order to educate their children with ASD? I thought about the choices available and the decisions that mothers need to make in order to find places for their children with ASD in Oman. I understand that parents of children with disability are operating within a very narrow and often inflexible system of benefits allowance and access of various resources (Ryan, & Runswick-Cole, 2008). In addition, writing my own story gave me the idea of taking the narrative approach as a methodological approach, which will be discussed in detail in chapter three. The next section will introduce the research problem and the background of the study.

1.3 Research problem and background

Prevalence rates of ASD internationally have risen dramatically. This increase is often attributed to changes in the definition of ASD and diagnosis criteria, (Fombonne, 2003). Alongside this, there has been an increase in the responsibilities of families of children with ASD, as they seek an education that suits their children’s needs. Children with ASD differ in their personality, characteristics, and ‘symptoms’ (Fombonne, 2003). Thus, there can be difficulty in identifying a unified and effective educational method that suits the majority of children with ASD. Some programmes are designed to support and address the needs of individuals with ASD; these include appropriate and effective educational practices. The difficulty for parents in Oman is even greater than in many other countries, for four main reasons. First of all, the prevalence of ASD is low in the documentation of the numbers of children with ASD, although there has been a rise in cases of ASD in Oman (Ouhtit et al., 2015). According to Ouhtit et al. (2015), “the low prevalence of ASD is related to different reasons, such as the absence of reliable diagnostic instruments” and the shortage of health services for children with ASD. In addition to that, there is a tendency for families in Oman to ‘hide’ their challenged children and thus limit their access to educational or remedial services (Profanter, 2009).

Secondly, in Oman, there are some centres that offer rehabilitation for all types of disabilities, including children with ASD, through the following programms and services: special education, occupational therapy, speech therapy, physiotherapy, psychological counseling, behaviour modification. However, most of these centres are private and expensive; they have been established recently, between the years 2010 and 2016; and most of them are located in the capital city of Muscat, which many parents cannot access.

Thirdly, the Ministry of Education’s (MOE) philosophy is to provide education for “all” children (MOE, 2008). However, from being an educator in the field of MOE for more than 19 years, I have noted that children with ASD are not included under the general umbrella of children with Special Education Needs (SEN), and children with ASD do not have the opportunity to be taught and educated in mainstream schools. As far as I know, many parents find themselves unable to enroll their children in any public or private centres that rehabilitate their children with ASD through focusing on treating their developmental problems and helping them integrate with their peers in normal classes in public education schools. There is continuous development in special education (such as the increased number of children with SEN and the special classes in mainstream schools) in the MOE and the Ministry of Social Development (MOSD), but this excludes children with ASD.

Fourthly, families do not have access to research, or they do not have the ability to locate educational strategies and methods that can be suitable for their children. Research in the field of ASD in Oman is limited to a medical perspective. As a researcher, I was unable to locate any research specifically focusing on parents' choices of educational strategies for their children with ASD (this will be discussed in detail in Chapter 2, section 2.6). I understand that Oman is a difficult site for my study because of the limited resources and educational services for children with ASD. However, it is worth investigating the choices parents (and, specifically, mothers) make in educating their children with ASD in a country with very limited educational services. I chose mothers because it is interesting to hear their voices about the challenges they face in choosing the education of their children with ASD and about their lives with them. It is also hoped that this research will provide an insight into the educational strategies that could be adopted by families in order to improve the educational outcomes of their children with ASD.

This study has its roots in my own experiences (see section 1.2) as the mother of a child with ASD who has experienced the process of making educational choices and decisions for him, and attended many other social events such as family meetings through my everyday contact with many mothers of children with ASD, I wondered about the strategies that mothers use in order to find places for their children, to socialise them in different events and the ways in which they experience their lives with these children in a country with limited resources afforded to them. I expected that mothers' experiences would vary, their perceptions would be different, and that they would have a range of different or common feelings about their lives with their children with ASD and about their choices and decisions about education.

This study was developed from my ongoing research interest in the field of ASD, I have thoroughly investigated the limited research in the field of ASD in Oman (see chapter 2). Therefore, the study contributes towards the emerging body of research with regard to ASD and mothers' experiences, and, to the best of my knowledge, it is the first attempt in Oman to explore the experiences and decision making of Omani mothers in their lives with their children with (ASD).

1.4 Research questions

Five research questions were developed to guide the exploration of mothers' choices in seeking education for their children, with the specific aim of linking mothers' experiences about the availability of education services provided by the MOE for children with ASD, as well as examining the difficulties and challenges faced by mothers when educating their children with ASD.

The research questions are:

1. How do mothers experience their lives with their children with ASD?
2. What is the meaning of 'education' for mothers in relation to their children with ASD?
3. What are mothers' experiences, perceptions, and feelings about the educational services provided by the government for their children with ASD?
4. What influences mothers' choices and decisions regarding educating their children with ASD?
5. How do mothers experience the challenges or barriers, if any, in choosing an education for their children with ASD in Oman?

1.5 Thesis outline

This thesis is organised into seven chapters. Chapter One is an introductory chapter, to present the background of the study.

Chapter Two provides a general overview of the Omani context and discusses education reform in Oman. It highlights the special education reforms in Oman by detailing all the particular elements and issues relevant to special education in Oman, which could help in contextualising responses to the research questions.

Chapter Three is dedicated to reviewing the relevant literature, providing a theoretical background to the study reported in the thesis. First, it identifies the key concepts of ASD and education. Then, it discusses literature in relation to different issues: the models of disability, how mothers experience ASD in their lives; early-age school choices; educational provision for children with ASD; parents' involvement in the education of their children with ASD; and challenges faced in educating children with ASD. Next, the chapter studies the experiences of mothers of children with ASD in finding and choosing an education for their children; mothers' perceptions of their child's independence and future; and mothers' experience with services for children with ASD. This chapter involved reviewing and critiquing studies conducted in various international contexts.

Chapter four focuses on the methodology used for this study by providing a detailed account of the research paradigm adopted, the study design, and phases. It also presents and justifies the data collection methods used, the nature and size of the research sample, the piloting process of the research tools, and the procedures for collecting and analysing data. Later I discuss ethical considerations and how issues relating to research quality were addressed.

Chapter Five presents and highlights the findings of the study, and provides an interpretation of these findings. The main areas from the data are presented and focused on in relation to different sources of data.

Chapter Six discusses the key findings in relation to the research questions, the study context, and the reviewed literature.

Chapter Seven summarises the key findings of the study, and presents its contribution to knowledge, implications, and recommendations. It further comments on the strengths and limitations of the study, and ends with my personal reflection on what I have learned from my experiences in carrying out this work.

1.6 Summary of Chapter One

This introductory chapter provided an overview of my starting point, by narrating my story as the mother of child with ASD. It also discussed the focus of the study by outlining the research questions, then explained the significance of the study and the investigated research questions. It concludes by listing the different chapters of the thesis. The next chapter provides, a detailed account of the study context.

Chapter Two: Overview of the Omani Context

2.1 Introduction

This chapter contextualises the study by providing background information about the development of education in Oman, specifically, in special needs and ASD. The chapter starts by outlining information about the Sultanate of Oman and the development of services in many aspects, not only in education. Then, it will explain the educational system and the development of services, educational, medical and social. This will be followed by a discussion of special education and ASD services in Oman, since the current study is exploring mothers' experiences about the services provided for children with ASD there. Then, the chapter will consider in detail ASD research in Oman.

2.2 Background of Oman and the development of services

Oman is located on the southeastern coast of the Arabian Peninsula. The country is bordered by the United Arab Emirates in the northwest, Saudi Arabia in the west, and Yemen in the south. It has a total area of 300,000 square kilometres of which 1,700 kilometres is coastline. The population is approximately 4.1 million (in mid-2018), of which 2.3 million are Omani citizens, with the remaining 1.9 million being expatriates of different nationalities. Oman is divided into eleven governorates: Ad Dakhiliyah, Ad Dhahirah, Al Batinah (North and South), Al Buraimi, Al Wusta, Ash Sharqiyah (North and South), Dhofar, Muscat, and Musandam (see Figure 2.1). These governorates varying their main geographical features comprising coastlines, mountains, and desert. It appears that this geographical variation, extensive desert areas, and large number of high mountains have impacted on the process of development in Oman and have affected the development of health, social, and education services provided for people living in Oman. This may have prevented the acceleration of the development process and increased the costs of service development in some of the rural areas.

Figure 2.1: Map of the Sultanate of Oman

2.3 The development of the educational system in Oman

The focus of this section is to explain the development of the educational system in Oman, and it will explain the progress that has been achieved in the last 50 years. Oman is classified by the World Bank as one of the developing countries (World Bank, 2019). It is classified along with countries such as Algeria, Yemen, Georgia, and Latvia. However it is also classified along with Malaysia, Chile, Poland, and Mexico as an upper-middle income economy. In other words, although its current state of development is low, its available resources are quite high. Therefore, Oman has a relatively good potential for development.

Education developed considerably, through a variety of stages. The beginning of formal education was in 1930, with only three primary schools in the country. Two were based in Muscat and Muttrah, and one in Salalah. These three schools included only 909 male students. There was also a different type of education, which took place in informal places like mosques, under trees, public spaces called ‘sabla’, or classrooms made from mud bricks. Subjects were mainly religious in content and included teaching of the Holy Quran and the basic principle of Islam, besides teaching Arabic and some basic numeric skills. The students progressed via a sole criterion, which was the quality of keeping to the Quran. Teachers did not receive any kind of training to qualify them for teaching. Most of them were selected for the job in terms of their ability to recite and comprehend the Holy Quran (MOE, 2008).

The crucial era came after 1970, when His Majesty Sultan Qaboos ruled the country. He gained prosperity, peace, and stability during this time, and established a variety of reforms and achievements to develop the Omani Society. He carried out large-scale projects for the development of the country and raised the standard of living of Omani citizens; for example, there have been great strides in educational, social, and economical aspects. One of the major priorities of the new Omani government has been education (MOE, 2008; MOSD, 2018).

Oman has witnessed an educational renaissance in the last few decades. Since 1970, the main focus has been to develop the youth of the country, to inspire them and to equip them for the future. This has been done through the expansion and the development of education (MOE, 2008). Therefore, in the spirit of youth being a key success in developing the country, the government established further boys’ and girls’ schools. It also commenced to spread the modern way of education as quickly as possible. His Majesty Sultan Qaboos stressed the importance of education in a speech. He stated:

“Education was my great concern, and I saw it was necessary to direct efforts to spread education. We have given the ministry of education the opportunity and supplied it with our capabilities to break the chains of ignorance. Schools

have been opened without taking into account the requirement. The important thing is that there should be education, even under the shadow of trees." (MOI, 1991, p. 19).

Oman's national education expanded rapidly during the 1970s and 1980s, with an increase in the number of private schools. The government encouraged the private sector to contribute to the education system. In the year 2015/2016, there were 715 private schools all over the country (MOE, 2019, MOSD, 2018). From 1970 to 2018, there was an improvement in all educational aspects such as private education, teacher training, higher education, and the educational system. Table 2.1 highlights the development in education in general, and in special education in particular (MOE, 2019, MOSD, 2018).

	1970	2019	Ministry
Education	909 male students 30 teachers 3 schools for boys	700,000 students 65,990 teachers 1,125 public schools 715 private schools 44 international (universal) schools	MOE
Special public classes in a mainstream school	0	1,471 students with learning difficulties 47 with a hearing impairment 155 with intellectual disabilities	MOE
Special public centres for children with all disabilities	0	2,453 children with different disabilities 27 Al-Wafa centres + 6 centres for different disabilities More than 415 professionals (special education teachers, occupational therapy, physiotherapy, speech therapy)	MOSD
A public intervention centre for children 1-15	0	190 children 1 centre 34 professionals	MOSD
A public centre for children older than 15 years old	0	260 children 1 centre	MOSD
Private special centres for	0	33 private centres	MOSD

children with all disabilities		837 children with different disabilities	

Table 2.1: Development in education and special education

The structure of the educational system in Oman is underpinned by Islamic rules and cultures (MOE, 2008). The system is co-educational in lower grades (ages 6-10), and single-sex in upper grades (ages 11-18). It used to encompasse two different types of educational services: general education and basic education. General education is of twelve years' duration (ages 6-18 years old). Since 1998, the MOE has gradually started replacing the general education system with a basic education service. Basic education is also for twelve years. It is divided into cycle 1, which is for four years (6-10 years old), and cycle two, of six years' duration (11-16 years old). Then, it is extended to two years of schooling, covering grades 11 and 12 (17-18 years old). Students who successfully pass grade 10 of basic education are promoted to study a specialised curriculum, taking into consideration students' choices of optional courses.

Education in Oman is free, but attendance is not compulsory. The MOE constantly reviews the educational system, to deliver a better education for children. (MOE, 2008). Education is organised centrally, as schools have to use the same curriculum provided by the MOE (MOE, 2019). Private schools may offer additional courses, subject to MOE approval. The same materials (textbooks, activity books, and teacher guides) are written, reviewed, edited, illustrated, and printed in Oman. Students in public schools cover the same number of hours assigned to each subject, applying the same timetable. There are different subjects taught, some of which are: Islamic studies, Arabic language, mathematics, sciences, English language, social studies, physical education, art, and music (MOE, 2008, 2019).

2.4 Special education in Oman

In order to investigate the research topic, this section will provide a historical background of special education in Oman. It is important to state that Oman is still progressing in the field of special education and is a novice in terms of experience in this field.

In the early-to-mid 1970s, the government's main educational focus was to provide educational services for the majority of students who did not require a specialised curriculum. Providing educational services for children with disabilities was considered to be expensive, and it was perceived that only a very small proportion of school-age students would benefit from such services. In 1978 and 1979, the government started to officially recognise that children with different disabilities had the right to a formal schooling (MOE, 2008; MOSD, 2018). Therefore, in the last few decades, there has been a movement towards the development of this, including provision for SEN students. One of the important movements was the establishment of the first school for students with special needs, called Al-Amal School, for students with hearing impairments. There was also Al-Fikriya School, to accommodate students with intellectual disabilities, and Omar bin Al-Khattab Institute, for students with visual impairments. These schools provide various educational programmes commensurate with the capabilities of each category, as well as providing rehabilitation and educational services. In the academic year 2015/2016, a total of 508 students received education in these three schools (MOE, 2015). Additionally, there are 27 public special centres, called Al-Wafa centres, and 33 private special centres that are presented in figure 2.2, which illustrates the distribution of private and public centres in governorates of Oman (MOSD, 2018). The figure (2.2) shows many centres in capital city, but fewer in some regions.

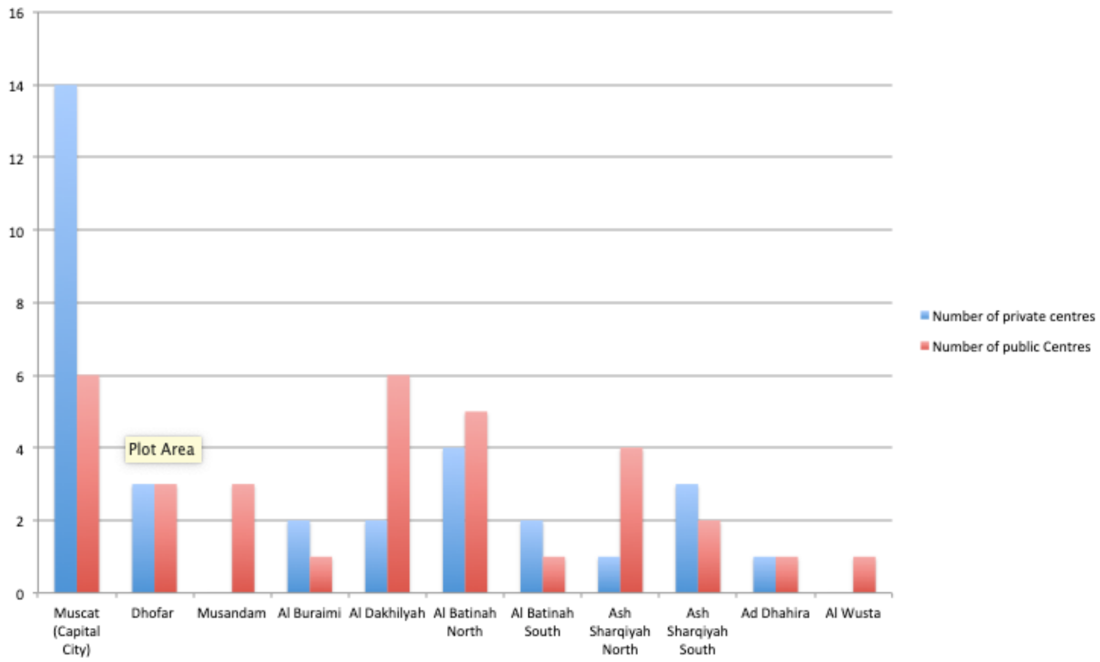


Figure 2.2: The distribution of private and public centres

Although there has been an improvement in the provision of special places or centres for children with disabilities, more effort is still needed from the MOE to integrate children with SEN into mainstream schools (Al Fawair & Al Tobi, 2015). There needs to be considerable coordination between the MOE and MOSD about disability, and there is a need to establish a disability-friendly environment and curriculum into mainstream schools to achieve the goal of education for all (Al Fawair & Al Tobi, 2015). The MOE and MOSD have established a shared responsibility and some further responsibility (for assessment) for the Ministry of Health (MOH). The MOE established a department for special education in each governorate, to provide special educational provision for children with disabilities (MOE, 2015). Another department, the Department of Associations and Community clubs, has been established in the MOSD that is responsible for providing a wide range of educational provisions for children with different disabilities. It also has the responsibility of supervising all other private special centres in Oman (see figure 2.3). These centres are different from schools in that they have professionals such as speech therapists, physiotherapists, special education teachers. Figure (2.3) provides an overview of the shared responsibilities towards children with ASD in Oman. There has also been an attempt by the

MOE to make programmes in schools more responsive to the needs of children with disabilities. The MOE also established an SEN section in 1984 that was later expanded into a full department (see Figure 2.3). As an outcome of establishing this, the MOE was in a better position to deliver educational programmes and to provide help and support for children with SEN.

A further step by the MOE has been to understand that many students with SEN could achieve better results in a setting where they are educated with typically developing children (MOE, 2008), rather than being segregated and isolated in special schools. Therefore, integrating a person with disabilities might assist in eliminating the effects of their disability, equip them with daily living skills, and develop their self-confidence. This is basically to guarantee the rights of people with a disability (MOE, 2008). In 2001, the MOE embarked on an inclusive programme that was implemented to include students with learning difficulties alongside their peers in mainstream classes (MOE, 2015). This programme is called partial inclusion, and refers to one strategy of inclusion that provides the opportunity for students with learning difficulties to spend only part of their school day or week having extra support (Kivirauma & Ruoho, 2006). The ministry also encouraged integration by establishing special classes in mainstream schools and providing support teaching in mainstream classes. This programme was developed to provide SEN students with opportunities to “interact, communicate, and build social networks with their peers, and to encourage norms of reciprocity, mutual assistance, and trustworthiness” (MOE, 2008, p 16).

Based on Omani traditions and Islamic commitments, there is an underlying principle of helping those with disabilities, in order for people with disabilities to contribute productively to building up a country’s economy. The principles of caring and rehabilitating people with disabilities emerge from Arab-Islamic values, the Omani constitutions, the National Charter, laws governing education and higher education, the Universal Declaration of Human Rights (UDHR) and the international United Nations on the Rights of Disabled Persons (Al Fawair & Al Tobi, 2015). These principles can be summarised as follows: a person with disabilities has the right to be integrated into the general life of a society; has the right to a higher education and employment, commensurate with their capabilities and qualifications; and has the right to sports and recreation. They also have the right to a suitable environment, and to preventative health and medical treatment. They have the right to obtain aids, and materials that support their education, training, and movement (Al Fawair & Al Tobi, 2015). These different understanding are stemmed from the different models of disabilities which will be discussed in chapter three.

2.5 Children with ASD in Oman

In order to understand Omani mothers’ experiences, perceptions, and feelings about the services available in Oman, there is a need to explore the current services from the documented data available in the Omani organizations’ websites (MOH, MOSD & MOE), which will be covered in this section.

Providing educational services for children with SEN stemmed from a willingness to obtain assessment, education, and rehabilitative care, to make them active, productive, and able to interact concurrently with life in the modern world. The following diagram provides a brief description of the services provided by three ministries: MOH, MOSD, and MOE.

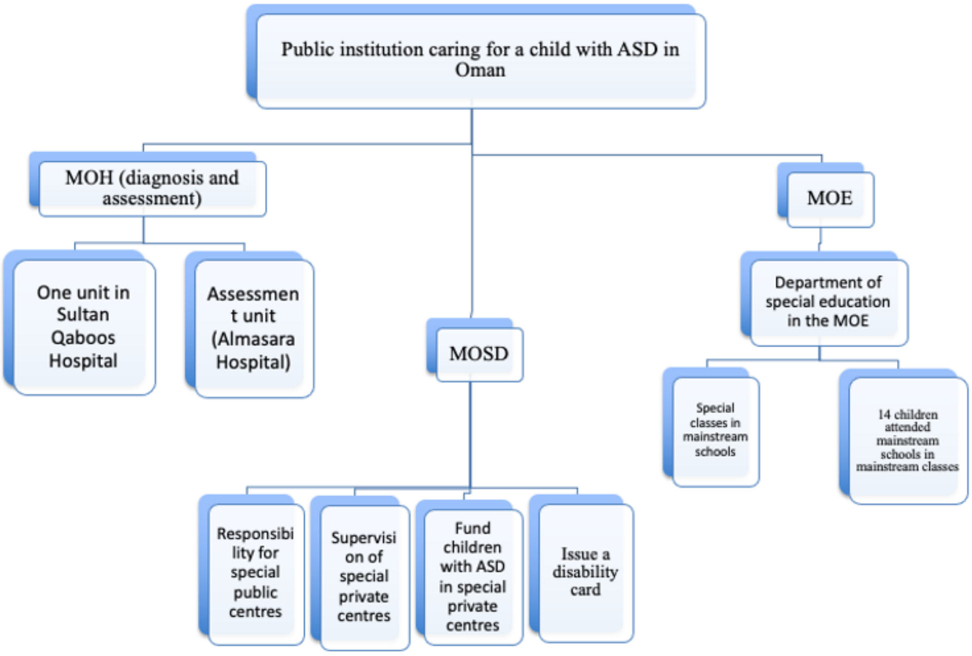


Figure 2.3: Public services for children with ASD and other disabilities

There has been great advocacy in terms of the provision of inclusive education in Oman, regardless of Oman being a novice country with regard to providing educational services for children with disabilities. However, the categories of SEN in inclusive classes have not yet included children with ASD. The integration of students with disabilities into regular schools includes those with hearing impairments and intellectual disabilities. Children with a diagnosis of a mental disability are also included in special classes in mainstream schools, but from my own experience as an educator in the field, if they are diagnosed with ASD, they will be rejected.

Individual efforts have started to include children with ASD in private centres. A psychologist and director of the Muscat Autism Centre commented in an interview with an Omani local newspaper: “We are in the unfortunate position of having to reject applications due to lack of space at the Centre.” (Al Riyami, 2013). In recent years, a public movement has established a few centres for ASD, and the MOSD in Oman recently funded care centres for disabled children, located in most governorates. There is also one early intervention centre, which is placed in Muscat. However, these centres cannot fulfil the needs of all students with ASD all over the country. The majority of children with ASD do not receive any form of formal education because of the guilt and embarrassment of their parents (Al-Farsi, 2015). They may fear negative attitudes from the public towards the person with ASD.

A recent movement towards rehabilitating children with ASD was started by the MOSD, to provide a number of special education services (such as occupational therapy, speech therapy, speech and psychological counselling, social, and professional configuration, physical activity, and its sensory effects) in rehabilitation centres for children with different disabilities. This suggests a medical model understanding which will be discussed in chapter 3. The number of children enrolled in these centres is 300. The MOSD provided rehabilitation services in other public and private centres for 1,037 children on the autism disorder spectrum during the educational year 2015-2016, along with providing a monthly income for 331 children (Al-Mamari, 2016). However, in recent statistics from the MOSD (2018), the number of children with ASD benefitting from the services offered by the MOSD was 989, out of a total number of more than 3,000 children (see Table 2.2). So nearly a third of the children benefiting from services are children with different disabilities.

Most notably, there is a lack of a national record and a national database of disability in general and ASD in particular. According to Al-Farsi, et al. (2015) epidemiological surveys from various countries indicate an increased prevalence of ASD. The epidemiology of ASD in developing countries, such as Oman, has generally indicated a lower prevalence compared to developed countries in the West. The low prevalence of children with ASD as a national record contributed towards the delay of the rehabilitation and education programs and services for ASD (Al-Farsi, et al. 2015).

2.6 ASD research in Oman

This section covers academic research into ASD in Oman but also presents the personal circumstances of those affected by ASD, and details governmental services.

Little data was available on ASD in Oman until the ASD Research Group was formed in 2008. This group started researching in the field of ASD, and to date, they have produced fifteen studies (thirteen studies were shown in the table) that have explored various aspects of ASD in Oman (see Table 2.2). This research looked at a number of factors, including the following: the prevalence of ASD (Al-Farsi et al., 2011a); awareness of ASD among school teachers (Al-Sharbati et al., 2015); awareness of ASD among healthcare providers (Al-Farsi et al., 2016); the socio-economic burden of ASD on families (Al-Farsi et al., 2013c); malnutrition among children with ASD (Al-Farsi et al., 2011b); the association between suboptimal breastfeeding and ASD (Al-Farsi et al., 2012); the development of mobile applications for screening ASD (Klein et al., 2015); and there are other studies that have been summarised in Table (2.2).

The ASD Research Group has made a great contribution in providing basic data for ASD in Oman, and may support the advance of infrastructure relevant to ASD and the medical field. However, most of the previous studies are quantitative and cross-sectionals such as Klein et al., (2015); Al-Sharbati et al., (2015); Al-Farsi et al., (2013a), or case control Al-Farsi et al., (2012); Al-Farsi et al., (2013b). These studies involved the use of structured questionnaires that included closed-ended questions, potentially affecting the ability to fully understand the context of the study (Creswell 2017). Almost all of these studies were conducted in Muscat (the capital city of Oman), which cannot represent or explain enough the experiences and perceptions of participants in the Omani context. Qualitative or mixed-method studies might be needed, in terms of providing detailed information to explain the context of ASD and its needs in Oman. It would seem to be essential to ascertain the perceptions not only of professionals but also those of mothers, who are less recognised in Omani research. This is because this group has not been explored before. The researchers in the previous studies proposed that research in the field of ASD should be continued, especially in Oman. There is a crucial need for more research to be conducted in the different fields associated with ASD, because the incentive for establishing services for children with ASD stems from awareness and recognition of the increased prevalence of the condition. It is a profound factor in improving the educational, social, and medical remedial services for those children and their parents (Ouhtit, 2015). Thus, there is an essential need to understand and discuss ASD, in order to develop medical and educational services for children with ASD. The following chapter will provide special attention to the understanding of educational intervention approaches and their importance in the field of ASD.

The study about the prevalence of ASD in Oman suggests a lower number compared to neighbouring countries. It affects 0.14 in 1,000 children, compared to 2.9 per 1,000 in the United Arab Emirates and 0.43 per 1,000 in Bahrain (Salhia et al., 2014) and the rest of the world (7.6 per 1,000 worldwide) (Baxter et al., 2015). However, these studies might not accurately present the actual number of ASD children in Oman as they used data extracted from one institution, which is believed to be the only formal source of records for children diagnosed with ASD in Oman. It seems that the prevalence of ASD in Oman, along with some other Arab countries, remains underestimated, due to ASD being undiagnosed or unrecognised in the community, especially for those with a mild form of the condition (Salhia et al., 2014). Al-Farsi et al. (2013) found that this discrepancy may be largely influenced by a variety of socio-economic factors, including differences in the cross-cultural presentation of ASD symptoms, a lack of professional services, and a lack of awareness and knowledge about ASD. Additionally, the low percentage of the estimated number of children with ASD was attributed to a lack of reporting and a lack of diagnosis, resulting from limited access to service centres (Al-Farsi, O, 2016; Ouhtit et al., 2015; and Al-Farsi et al., 2011b). It is important to mention that all Omani citizens or non-citizens living in Oman are served by one single child psychiatry unit located in Muscat. The majority of the population may find it challenging to reach this unit for diagnosis or treatment. They may struggle financially to seek the required follow-up session for their children in this unit. One of the reasons for this financial struggle is the nature of some governorates in Oman, which are adjacent to international borders such as Buraimi, Shinas, and Musandam. People living in these areas may seek services closer to their residence, so they have not been reported in Oman. In addition to that, there may be a lack of awareness from children's parents about ASD, and they may fail to understand or recognise symptoms associated with ASD. Thus, they may fail to seek a diagnosis and treatment for their children (from a medicalized perspective, see section 3.2), especially for children who suffer from mild forms of ASD (Al-Farsi et al., 2011).

The rise of ASD will place a great demand on health and social care systems and will impact the economy of the country, in terms of supporting individuals with ASD and their families. A study of the financial burden of taking care of children with ASD in Oman was undertaken among 150 families (80 families from medium-income groups and 70 families from low-income groups) (Al-Farsi et al., 2013c). The findings indicated that 8% of mothers in these families had resigned from their job to care for their children with ASD, and 5.7% of them were from low-income families. 15% of the monthly family income would be allocated to their child with ASD in Oman. The cost might be varied based on the child's age, because during childhood, the highest costs are allocated to special education services and parental productivity loss, whereas costs during adulthood fall heavily in residential care or supportive living accommodation and individual productivity (Knapp et al., 2009). Therefore, healthcare professionals and community identify a need to improve support services for families of children with ASD, in order to ensure that families are not affected throughout their children's lifespan (Al-Farsi et al., 2013a; Al-Farsi et al., 2016;

Al-Farsi et al., 2011a).

With regard to ASD research in Oman, studies have been limited in this field. Until 2008, little information was known about ASD in Oman because of this lack. A recently formulated ASD research group at Sultan Qaboos University initiated research activities that resulted in important findings in the field of ASD. Despite this, fewer than seventeen pieces of research related to ASD were conducted in the years 2010 to 2016, shown in Table (2.2). Since then, I have found other studies published by other researchers as a work to get PhD degrees.

Table (2.2) shows that ASD research in Oman is limited and is mostly in the field of medicine. The ramifications of these studies would show briefly the need for more studies like the current one in the field of ASD parents' and mothers' experiences. (Green = prevalence; blue = social approach; yellow = medical approach; orange = Diagnosis; and grey= both social and medical approach).

No.	Authors and Title	Method	Number of Participants	Findings
1	Al-Farsi, Y. M., Al-Sharbati, M. M., Al-Farsi, O. A., Al-Shafaee, M. S., Brooks, D. R., & Waly, M. I. (2011a). Brief report: Prevalence of autistic spectrum disorders in the Sultanate of Oman. Journal of ASD and Developmental Disorders, 41, 821–825.	Cross-sectional study to estimate the prevalence of ASD among 0–14 year old children. (questionnaire)	113 parents	The findings reported low prevalence of ASD in Oman cause by under-diagnosis and under-reporting.
2	Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al Shafaee, M. A., & Deth, R. C. (2011b). Malnutrition among preschool-aged autistic children in Oman. *Research in Autism Spectrum*	A cross-sectional study	128 children with ASD (3–5 years of age)	ASD children of preschool age in Oman showed a general tendency towards malnutrition. Extensive educational and advisory efforts are called for in order to mitigate this problem and its corresponding complications among this

	Disorders, 5(4), 1549-1552.			vulnerable group.
3	Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al-Shafaee, M. A., Al-Khaduri, M. M., ... & Deth, R. C. (2012). Effect of suboptimal breast-feeding on occurrence of autism: a case–control study. *Nutrition*, 28(7-8), e27-e32.	A case–control study	102 children with ASD and 102 matched healthy controls	An increased risk of ASD has been associated with suboptimal breast-feeding practices in Oman. The risk decreased in a dose-response fashion with increasing periods of exclusive breast-feeding for the first 6 months and with periods of continued breast-feeding during the first 2 years of the child's life.
4	Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M. A., Al-Farsi, O. A., Al-Khaduri, M. M., ... & Deth, R. C. (2013a). Levels of heavy metals and essential minerals in hair samples of children with autism in Oman: a case–control study. *Biological trace element research*, 151(2), 181-186.	A case control study Parental interviews were held and dietary intake questionnaires completed in conjunction with the collection of hair samples	27 children with ASD and 27 matched non-ASD controls	Children with ASD had higher levels of heavy metals in their hair than non-ASD controls and had higher levels of the essential minerals sulfur, sodium, magnesium, potassium, zinc, and iron, but lower levels of calcium and copper in their hair samples.
5	Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M., Al-Farsi, O., Al-Fahdi, S., ... & Al-Adawi, S. (2013b). Variation in socio-economic burden for caring of children with autism spectrum disorder in Oman: caregiver perspectives. *Journal of autism and developmental disorders*, 43(5), 1214-1221.	A cross-sectional study	150 caregivers of children with ASD from two types of socio-economic status (SES) groups (low-income and middle-high income)	Caregivers felt that there is a lack of adequate remedial and rehabilitation services in the country. Similarly, caregivers expressed reservation in endorsing the quality of the services offered by the mental health profession. The net socio-economic outcome appears to be downward social mobility, as many of the caregivers relinquish their income-generating jobs in order to focus on their cognitively, socially, and behaviorally challenged children.

6	Al-Farsi, Y. M., Waly, M. I., Deth, R. C., Al-Sharbati, M. M., Al-Shafaee, M., Al-Farsi, O., ... & Al-Adawi, S. (2013c). Low folate and vitamin B12 nourishment is common in Omani children with newly diagnosed autism. *Nutrition*, 29(3), 537-541.	A case–control study Blood samples were collected from each of the 40 cases and 40 controls matched for age, sex, and weight	80 Omani children (40 children with ASD versus 40 non-ASD controls)	The ASD cases showed significantly lower levels of folate, vitamin B12, and related parameters in dietary intake and serum levels. This data showed that Omani children with ASD exhibit significant deficiencies in folate and vitamin B12, and the study calls for increasing efforts to ensure sufficient intake of essential nutrients by children with ASD, to minimise or reverse any ongoing impact of nutrient deficiencies.
7	Al-Sharbati, M. M., Al-Farsi, Y. M., Ouhtit, A., Waly, M. I., Al-Shafaee, M., Al-Farsi, O. & Al-Adawi, S. (2015). Awareness about autism among school teachers in Oman: A cross-sectional study. *Autism*, 19(1), 6-13.	A cross-sectional study	164 Omani teachers from 5 schools	The research found that misconceptions about ASD seemed to be common among mainstream teachers in Oman. This was related to sociocultural patterning, as well as conflicting views from community and media.
8	Al-Farsi, Y. M., Al Shafaee, M. A., Al-Lawati, K. S., Al-Sharbati, M. M., Al-Tamimi, M. F., Al-Farsi, O. A., Al Hinai, J. A. & Al-Adawi, S. S. 2016. Awareness about Autism among Primary Healthcare Providers in Oman: A Cross-Sectional Study. *Global Journal of Health Science,* 9**,** 65.	A cross-sectional study	113 working at primary healthcare centers	The health providers appear to have suboptimal awareness of etiological factors relevant for the development of autism, its common signs and symptoms, perceived correlates, as well as the social dimension. The number of years in practice has little bearing on awareness.
9	Ouhtit, A., Al-Farsi, Y., Al-Sharbati, M., Waly, M., Gupta, I., Al-Farsi, O., ... & Al-Adawi, S. (2015).	-	-	In Oman, the lower reported rate of ASD could be directly related to various sociocultural

	Underlying factors behind the low prevalence of autism spectrum disorders in Oman: Sociocultural perspective. *Sultan Qaboos University Medical Journal*, 15(2), e213.			factors. This potential discrepancy in the prevalence rate of ASD may stem from cross-cultural variations in the manifestation of behavioural and emotional disorders. If the current, apparently low, prevalence in Oman is in fact just a consequence of under-diagnosis and under-reporting, a concerted effort is needed to increase public awareness of ASD.
10	Klein, T. J., Al-Ghasani, T., Al-Ghasani, M., Akbar, A., Tang, E., & Al-Farsi, Y. (2015). A mobile application to screen for autism in Arabic-speaking communities in Oman. *The Lancet Global Health*, 3, S15.	Developing software to screen children with ASD	130 participants: 65 caregivers of children with ASD and 65 caregivers of TD children	The team have developed a mobile application to screen for autism in Arabic-speaking populations that is both sensitive and specific.
11	Al-Kindi, N. M., Al-Farsi, Y. M., Waly, M. I., Al-Shafaee, M. S., Bakheit, C. S., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Comparative assessment of eating behaviour among children with autism to typically developing children in Oman. *Canadian Journal Clinical Nutrition*, 4(2), 51-64.	Anthropomorphic data and clinical characteristics were sought from the parents. Brief Autism Mealtime Inventory was used to evaluate the mealtime behaviour of children.	Parents of 163 ASD and 212 TD children, aged 4 to 13 years, participated in the study	The study provided information that children with ASD display more problematic behavior than typically developing children. Although problematic behaviour in ASD children is not considered a core feature of autism, it can, however, be associated with part of the phenotypic features of ASD.
12	Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case–control study. *Neuropsychiatric*	A case–control study	220 parents (107 fathers and 113 mothers)	All indices of stress, depression, and anxiety were higher in caregivers of children with ASD compared to other caregivers in the control group, and caring for children impacts the mental health status of caregivers.

	disease and treatment, 12, 1943.			
13	Al-Farsi, O. (2016). The *Quality of life among Parents of Children with ASD Spectrum Disorder in Oman.* Sultan Qaboos University. Unpublished PhD thesis.	A cross-sectional study	220 parents	This study investigates the quality of life among parents of children with ASD in Oman. The study aimed to find out whether the behaviour and sleep problems of children with ASD affect parents' stress, parents' burden and parents' low-quality sleep.
14	Al-Wahaibi, A., Al-Hajry, M., Al-Bahrani, Z., & Al-Busaidi, K. A. (2016). The Development and Acceptance of Autism Advisory Expert System. *International Journal of Computing & Information Sciences*, 12(2), 179.	This research paper aimed to develop an expert system designed to offer parents an initial diagnosis for ASD	-	The system covers five diagnoses: autism in low, medium, and high levels; Asperger's disorder; and childhood disintegrative disorder (CDD). Once the system gives the parents a diagnosis, it also offers a set of general advice for parents to follow so their child's case won't worsen. The system was evaluated by a domain expert and a set of potential users who listed the benefits, limitations, and risks.
15	Alshekaili, M., Al-Balushi, N., Al-Alawi, M., Mirza, H., Al-Huseini, S., Al-Balushi, M., ... & Al-Adawi, S. (2019). Risk factors underlying depressive symptoms among parents/primary care providers of kids with autism spectrum disorder: A study from Muscat, Oman. *Perspectives in psychiatric care*.	A cross-sectional analytical study	120 participants	This study suggested that depressive symptoms, as elicited by the PHQ-9, are common among parents/caregivers of children with ASD seeking consultation at a tertiary care center in Muscat, Oman. The rate of depressive symptoms appears to be higher when using the PHQ-9 compared to other instruments. Predictors of depression from this study included socio-economic status and being the sole parent/caregiver. Of the two, lower income appears to bear the brunt of vagaries of depressive symptoms.

16	AlMaskari, T. S. (2018). *A mixed methods study exploring the barriers and facilitators of screening for autism spectrum disorder in Oman*. University of Glasgow. Unpublished PhD thesis.	An exploratory mixed methods design	Two focus groups, seven nurses and six GPs. Questionnaire (n=571)	The findings revealed that both nurses and GPs believed that introducing screening for ASD would be a positive step. However, they felt overwhelmed by their responsibilities and believed that their workplaces lacked the necessary infrastructure. Practitioners’ awareness of ASD services was identified as poor, as were the essential skills required for undertaking screening.
17	Al ‘Omairi, K. H. (2019). *The effectiveness of a parental guidance program for developing stress management skills in a sample of parents of children with autism in Sultanate of Oman.* Ain Shams University. Unpublished PhD thesis	Semi-experimental method	10 parents divided in 5 groups	After verifying the psychometric tools of the study, the results showed that there was a statically significant effect on the group of the study dealing with psychological stress among parents of children with ASD.

Table 2.2: A summary of ASD research in Oman

2.7 Summary of chapter two

Educational development and special needs services in Oman have gone through a rapid growth in all sectors, including health, social, and education. The number of services and the availability of activities offered to children with SEN, including children with ASD, have increased. The establishment of research in ASD has had an impact on the increased knowledge of ASD in worldwide and in particular a developing country such as Oman. However, there is still a need for more research to focus on the educational side, the parents’ quality of life and well-being, and the experiences of mothers of children with ASD, which will be discussed in Chapter three. It will also review the international research literature to provide a basic background that might inform an understanding of ASD and education, and of mothers’ experiences of their lives with their children with ASD.

Chapter 3: Literature Review

3.1 Introduction

The aim of this study is to explore the experiences of Omani mothers in their lives with their children with autism spectrum disorder (ASD) and consider the decisions and choices they make about their children's education. The main purpose of the chapter is to examine the literature on mothers' experiences regarding their children with ASD, their choices of education for them, and their strategies for finding and accessing services for their children with ASD. There has been some research in some countries into these topics, but limited research has taken place in Oman or other Arab countries. In order to position this study within the existing body of literature with regards to both ASD and mothers' experiences, this chapter will look at areas of the study including the following: ways of understanding disability, definition and nature of ASD; theories and causes of ASD; and its prevalence and diagnosis. These will help me as a researcher to develop a better understanding of ASD. The chapter will also discuss some areas around parents' educational preferences for their children with ASD. In addition, it will be presented and organized around the research questions that were stated in the first chapter. The key concepts of the research questions are these: ASD; education for children with ASD; mothers' experiences in their lives with their children with autism spectrum disorder (ASD), and the decisions and choices they make about their children's education.

This chapter will examine the meaning of ASD and the prevalence of ASD internationally, as well the definition of ASD and diagnosis. A definition of ASD is needed for this study in order to understand whether the mothers in the study are aware of the range of meanings, which would have an effect on their experiences. Two other areas explored in this review in this literature review are mothers' educational preferences for children with ASD when considering their education, and mothers' lives with their children with ASD.

3.2 Ways of thinking about disability

Before I begin discussing ASD in Oman, I intend to discuss disability in general (although the issue of disability is broad, Rogers, 2011), and I will then narrow this down to discuss ASD as one type of disability that will be explored in depth in this research. There is a need to look at various ways of thinking about disability (including the medical, religious and social models, and others) in order to understand aspects related to parents' experiences and their understanding of disability. The reason for starting with different aspects of disability was derived from an understanding of the complexity of disabled people and their families' lives. This will be shown as the thesis progresses. In addition, to the best of my knowledge, there is a lack of research in Oman and in the wider region in the field of disability, as well as in the field of ASD (as it was dicussed in section 2.6 about different research in Oman). Table 2.2 (p. 35-40, above) shows that some of these pieces of research related to ASD conducted in the years 2010 to 2016 ASD adopt a medical lens when exploring Autistic Spectrum Disorders (ASD).

Disability is highly debated, and a variety of different meanings have been attached to it (Goodley, 2011). It can be interpreted from cultural and religious perspectives, located within the disabled individual's body and mind – as in the medical model – or seen as a result of social stigma and barriers (Goodley, 2011). Disability has been used to oppress and discriminate against disabled people in order to collect for charities or to identify disabled people as deservers of pity and sympathy (Goodley, 2011). In contrast, it has also been used to empower and free disabled people from problems they face in their daily life experiences (Goodley & Runswick-Cole, 2016). This contestation and debate around disability can be explored through the lens of a number of models that will be presented and analysed in this section to inform my research. This includes the following: the religious/moral model; the medical model of disability; and the social model of disability, disablism, and ableism.

3.2.1 The religious/moral model of disability

There are similarities and connections between cultures, people, and religions that have varying attitudes towards disability. According to the religious model, disability can be considered as punishment from God or a result of evil spirit possessions or might be understood as a gift from God that has angelic characteristics (Treloar, 2002). These attitudes varied in different studies based on the strength of parents' belief in God – some people showed satisfaction with 'God's creation' while others showed anger at 'God's fate' for creating their children as disabled. A study conducted in United State of America by Treloar (2002) on how disabled people and their families use spiritual beliefs to find meaning in their impairments recounts some stories related to disability and punishment. Treloar (2002) found out that disabled people can have both positive and negative attitudes towards God for making them disabled. She explained that despite the negative attitudes exhibited by non-disabled people towards disabled children and their families, in some cases their belief in God led them to be satisfied with having disabled children. Some people reported positive attitudes and satisfaction with 'God's will' while others showed anger towards God for making them disabled. This discontent with God's will led them to feel despair, hopelessness, and resentment. Another study in UK by Godina (2012) also reported that religious understanding of disability played an important role that influenced parenting practices, goals and emotional climate at home (Godina, 2012). She highlighted the positive effect on parents and family life across different faith and culture perceive typical children as blessing. Parents may benefit from support from people who share similar value system and from local religion organization

I will move from a general discussion of religious texts to focus on Islam as this may be the most relevant discussion to my study, as Islam is the common religion in Oman. In relation to Islam as one of the existing religions, the term 'disability' does not exist in the two primary sources of Islamic religious (Quran and Sunnah of Prophet Mohammed) as a direct word (Bazna & Hatab, 2005).

Disability in Islam is discussed in Hasain, Shaikh, and Shanwani (2008, p.31) who state that “Islam views disability as morally neutral, neither a blessing nor a curse: it is considered an inevitable part of the human condition, one that Muslim society and individuals must address”. In the Muslim holy book, the Quran, there is no term that could equate to the modern term ‘disability’; rather, there are other specific Arabic Hadith, which are the sayings and deeds of the Prophet Mohammed. In these sayings (Hadith), there are terms referring to disability such as the words ‘blind’, ‘deaf’, ‘lame’, and ‘leper’ to describe disabled people (Hasnain et al., 2008). The terms that could be relevant to the term ‘disability’, such as ‘weak, ‘sick’, ‘orphan’, ‘indigent’, and needy (Bazna & Hatab, 2005). These differences are recognised neither as punishment nor as praise but as part of human beings’ diversity and experiences, and it is the responsibility of society to make sure that each individual’s requirements are met (Bazna & Hatab, 2005). In Islamic activities, individuals are given the right to perform the Islamic activities in terms of their local culture, and to an extent that corresponds with their individual requirements in terms of dis/ability, age, and gender. In the Quran it was stated that “God does not burden any human being with more than he is well able to bear” (Al-Baqarah, v.286, as translated Asad, 1980). This reflects that Islam has a positive recognition of people’s differences as ‘normal’ aspects of human diversity, but having an impairment can be challenging.

Disabilities and impairment are two concepts related to each other’s, but they have different meanings. Impairments are things that happen to individuals’ bodies or mind that can be problematic, while disability is about the extent to which having an impairment in a particular society, a particular time or place which leads to disadvantages and discrimination (Shakspeare, 2006). The differentiation between the terms ‘disability and ‘impairmnet’ is when referring to obstacles/barriers in a society means ‘impairmnet’ and when referring to disabled people bodies we means ‘disability’. However, impairment restrict disable people activities in society and their interaction between body and society.

This section provides an understanding of how disability has, in part, been socially constructed through these religions. In Oman, people also practice the religious model politically and socially which will be discussed in section (3.2.6).

3.2.2 Medical model of disability

The medical model of disability has been dominant since at least the 19th century (Goodley, 2011). Disability in this model is defined as “an individual’s defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being” (Sieberas, 2008, p. 3). This defect is meant to be located in the body or mind of a person labelled disabled. Goodley (2011) points out that disability is conceptualised as a defect of the mind or body within a person instead of within society and that disability can be fixed and resolved through the power of medicine and the paramedical professions (Goodley, 2011). They claim that only through this route can disabled people be enabled to function ‘normally’ in life (Goodley, 2011). It represents the way supporters of the social model described medical and psychological approaches to disability

The benefits of this discussion of the models are that it can lead policy makers and services managers to focus on their work in compensating people with disabilities and target specific benefits towards providing services. This can be done through providing an empirical model of knowledge development (Kane, 1982). According to Kane (1982), the medical model provides a common language for communication within the field and the basis for an organised body of knowledge about what is the effectiveness of treating various ‘problems’. Therefore, there is a need to understand a disability and its deficit in order to assure that the appropriate person receives the service that meets his/her needs (Kane, 1982). Skidmore (1996, p.34) conceptualizes that “special needs as arising from deficits in the neurological or psycological make-up of the child, analogous to an illness or medical condition”.

However, the efficacy of this model in resolving the problem of disability has been questioned, and its conception of disability being located solely within an individual has been highly criticised since the 1960s (Goodley, 2011). This is because the medical model fails to promote a more inclusive society or to eliminate – or at least reduce – the various forms of prejudice and discrimination that disabled people face in society and in educational institutions in particular. This model, however, leads to and encourages the exclusion of disabled students from special schools and classrooms within mainstream schools, and to disabled children being taught by 'special' educators who claim to have a unique knowledge and expertise to cater to disabled children's different requirements (Goodley, 2011).

The medical model lens adopted by school practitioners may affect disabled children's experiences in schools by assigning psychologists and 'special' educators to diagnose and examine disabled children's minds and bodies using biased tools, leading them to be labelled and thus excluded (Farrugia, 2009). The medical model assumes that disability limits people's activities and participation, thus they should be excluded in order to receive 'special' care and treatment from 'special' professionals. The impact of this model on disabled people and children does not stop there, extending to include perceiving disabled people as either overly independent, which in either case promotes stereotypes and represents disabled people as being in need of pity and charity. The representations of disabled people as being in need of pity and charity are a direct consequence of viewing disability as a personal tragedy via the medical model of disability. This has created a distinction between disabled and non-disabled people and has significantly contributed to the spread of negative attitudes towards disabled people and the exclusion of disabled people, because it reinforces a negative image of disability and depicts disabled children as being a problem. In other words, it is their responsibility to fit into the world as it is. Medical model proponents believe that disabled people need to adopt to their surrounding environment. Disabled people could do more to help themselves participate 'normally' in society's activities (Goodley, 2011); otherwise, they should be excluded from special education institutions/schools or housed in self-contained classrooms within mainstream schools if medical and normalisation interventions fail to remediate the individual's mind or body.

According to the social model and at an institutional level, that “learning difficulties arise from deficiencies in the way schools are currently organized (Skidmore, 2004, p. 10). Then there is a need for schools to restructure their policies to “produce a system of schooling which is better adapted to meeting the educational needs of all pupils” (Skidmore, 2004, p. 7). The school would therefore, adapt and respond to the diversity found in the students and no group would require a so-called ‘special’ form of educational provision (Skidmore, 2004). Thus, it empowers and privileges people considered ‘normal’ or ‘able’ at the expense of people labelled disabled because it sees people labelled as such as unproductive and less human (Davis, 2013). This not only affects how disabled people view themselves, but also affects where they live, where they receive their education, the support they receive, their relationships with others, and their job opportunities.

In some ways, the medical model may create major problems in the lives of disabled people and their families and allies by standing for and supporting the creation and perpetuation of different forms of dis/ableist discourses and practices (Goodley, 2011), including – but not limited to – labelling and appreciation based on ability; oppressive language; inaccessibility of spaces; discrimination in education and employment; charity; pity; diagnosis; labelling; and exclusion (Thomas, 2002). The medical construction of disabilities such as ASD affects the disabled individual in ways that are pessimistic, individualistic, and focused on deficit and inferiority/ superiority. Parents deploy discourse drawn from medicine and the real world in order to understand their children and negotiate an identity for themselves and their children (Landsman, 2005). It protects their self-esteem and helps them accept the difficulties of their children. Parents of children with ASD may experience considerable exclusion due to their children inappropriate behaviour, which may lead to feelings of shame and exclusion from social activities (Landsman, 2005). The complex and challenging nature of children with ASD are the causes of blaming parents for their children’s behaviour. Fisher and Goodley (2007) also show this in interpreting that ‘the other’ parents’ adapt medical knowledge about their child’s impairment and disability.

This model is evident in the Omani context and the research discussed in the chapter two adopt a medical lens, such as the Al-Farsi et al., (2013b) investigated variation in socio-economic burden for caring of children with autism spectrum disorder in Oman: caregiver perspectives.

3.2.3 Social model of disability

The social model of disability played a role in understanding disability and helped in the movement of disabled people (Goodley, 2011, Shakespeare, 2006). The social model originated as a reaction to previous models, to expose, problematise, and challenge the dominant social oppression, inequality, and exclusion of disabled people in the society in which they live (Goodley, 2011). Shakespeare also points out that personal and social factors influence disabled people and influence in their interactions. This model of disability considers that instead of a disability originating within an individual, it originates from society. Disability results from barriers in society and the environment surrounding an individual, such as physical barriers or attitudinal barriers (Goodley, 2011; Shakespeare, 2006). When understanding this model, it helps us understand that problems in terms of disability do not belong solely to disabled people but to the construction of society and its social consequences. The model also strives to accomplish a crucial goal, which is to end exclusion and oppression and to support independent living, active participation, and empowerment of disabled people and the society in which they live (Goodley, 2014). This reveals that disability is a result of a complex collection of social ideals and disabling attitudes, institutional structures, and governmental policies (Goodley, 2011; 2014). Therefore, the social model attempts to remove disabling barriers (Goodley, 2014) that include, for example, inaccessible education; information; communication systems; physical public spaces and transportation; discriminatory legislation; health and social support services; and the devaluation of disabled people through pity, charity, staring, and negative images in the media and public (Oliver, 2004). This clearly shows how the social model was critical in exposing and problematising the status quo of social construction, and it demands that the social world must change (Goodley, 2014). The social model provides a theoretical and practical basis to generate policies and practices, to achieve the major aim of eradicating inequalities and the exclusion and oppression of people labelled disabled (Batnes & Mercer, 2005).

The social model helps to recognise barriers that make life harder for people with a disability and removing these barriers can create equality and offer them more interdependence, choice, and control (Skidmore, 2004). The social model understands disability as a societal issue, calling for a reform in the practices and attitudes of society.

However, there are critics who argue that the social model is a limited explanation for what is happening to people with disabilities in the modern world and that there is a need for different models, to understand their differences. For example, the failure of the mode to encompass the personal experiences of pain and limitation which is often an art of impairment (Shakespeare & Watson, 2001).

3.2.4 Disablism and ableism

Another way of exploring our understanding of disability is through the lens of disablism and ableism. Goodley (2011), argues the medical model in particular perpetuates dis/ableist discourses and practices.

Disablism is a form of social oppression similar to racism and sexism (Goodley, 2011). Thomas (1999, p. 8) described it as ‘difficult to define’ because it involves complex and interrelated issues. It can be understood as ‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being’ (Thomas, 1999, p. 60). Thus, disablism involves a range of exclusionary practices against disabled people across political, economic, educational, emotional, intimate, and personal dimensions (Goodley, 2014). It also affects disabled people externally and internally – Thomas (1999) categorises this into structural disablism (barriers to doing) and psycho-emotional disablism (barriers to being). The former refers to material barriers that have been a major concern of the social model in how normalcy is constructed to discriminate against and to exclude disabled people. This gives disabled people experiences and feelings of “being excluded from physical environments” and reminds disabled people that “they are different and can leave them feeling that they do not belong in public and private spaces”.

Thomas, (1999, p. 60) defines psycho-emotional disablism as “the socially engendered undermining of emotional well-being”. Disabled people can experience exclusion intentionally or unintentionally through people who are close to them, such as family members, relatives, and friends; people who have direct interaction with them, such as teachers or professors; or through strangers who meet them (Thomas 1999). This understanding views schools as an important part of society that can enable or disable individuals (Goodley, 2014). Mainstream schools are bound up with inequalities and exclusion and contribute to the expansion of disablism into the wider society. More specifically, school professionals can be responsible for perpetuating different forms of disablism in schools where they are employed. This means that schools can play a vital role in challenging disablism, not only at an educational level but also at a societal level (Beckett & Buckner, 2012). This is only if they acknowledge that disabled people are disabled by school systems and by their minds and their bodies (Goodley, 2011), and then rearrange policies and practices accordingly to respond to the requirement of all students, irrespective of differences. In order to better understand disablism, there is a need to explore ableism because they are interrelated with one another and they feed into the production of each other (Goodley, 2014).

Similar to disablism, ableism is connected to the beliefs and practices of normalcy (Goodley, 2014). Ableism and disablism have the same origins that are deep-seated: the oppression, discrimination, and exclusion of people who do not fit into the normative assumptions of a particular society (Goodley, 2014). Goodley (2014) and Goodley and Runswick-Cole (2016) determine these factors as feeding into the production and survival of one another. Ableism is about beliefs and practices that favour a set of abilities related to the human mind and body but devalue and exclude those who do not possess them. As

Wolbring (2008, p. 253) stated, ableism is the favoritism “for species-typical normative abilities leading to the discrimination against [disabled people] as less able and/or as ‘impaired’ disabled people”.

Some views may be that mainstream schools are the right placements for all learners; however, the problem is that these schools require learners to have the same characteristics and to perform academic and non-academic tasks in ways considered to be ‘normal’, which can create a problem for disabled people. Wolbring (2008) states that schools that favour ‘normal’ students could lead to marginalisation or a failure to meet the requirements of those students who do not meet the standards of ‘normality’. Therefore, it is crucial for schools to understand that it is their responsibility to eliminate ableism, to meet the requirements of all students irrespective of differences. In order to apply ableism in schools, it is important for teachers to include disabled individuals as part of a school’s overall environment and to make all possible effort to support the success of all students. In this way, disabled and able-bodied students can understand and learn about each other. The inclusion of disabled students in mainstream schools promotes their recognition in all aspects of society. It is also important to teach disabled learners through different methods, to give them the opportunity to use the skills and learning strategies that are most suitable and effective for them, and it is equally important to have high expectations about disabled pupils and their abilities to perform their educational tasks by eliminating the most ableist of beliefs: that disabled pupils are ‘unable’ or ‘less able’ (Wolbring, 2008).

3.2.5 Which understandings of disability influence mothers’ experiences?

In this section, I will focus on how different understandings of disability may influence the ways in which the mothering of children with disabilities takes place.

The medical model of disability focuses on impairment and views a reduced function because of the child’s deficit. According to Drake (1999) there is a tendency when parents talk about their children with disabilities for them to construct their experience within a medical framework, which identifies a separation between ‘normal’ and pathological. Parents of children with disabilities are reliant on information from medics in order to understand their children’s characteristics and in order to address their needs and seek services for them. This understanding may lead mothers to have a desire to ‘fix’ their child, based on the belief that they cannot be good mothers unless they maintain their child’s linear progress (Landsman, 2005). This in turn could lead to a higher level of maternal stress and unhappiness due to having a child with disability. This highlights the problematic way in which mothers of disabled children are represented by community through ‘super mum’ perspective. Hays (1996) has talked about intensive mothering where mothers are the main care givers to the children who spend a lot of time to meet their children’s needs giving their time and energy. Shirani, et al., (2012, p. 26), when examining mothering term in the UK, highlighted an assumption that exists where “mothers in most cases have the ability to control and shape the lives of their children”. Mothers have been positioned as all caring and self-scarifying (Hays,1996). A study by Johnston and Swanson, (2003) reported that mothers tried to educate their children to be polite and well behaved; they set limits and had rules even if sometimes they lost their tempers. Mothers of children with disability undertake multifunctional roles such as covering the on-going needs of the child, interest, love and continuous attention (Landsman, 2005). It is arguable that being a mother of a child with disability is similar to being a mother of a child without disability, but it is also different. Being a mother, in general, needs dedication and put the needs of the baby first (Horne et al., 2005). However, it also differs through adding new roles and activities to them beside the typical daily activities.

Conversely, the social model of disability proposes that the relation between reduced function and the experience of disability is contingent on environmental, social, and cultural influences (Norish, 2002). There has been a parental commitment to promote a child’s development, and the result has been less focus being placed on addressing the disabling condition of society (Rizvi, 2017). According to Rizvi (2017), medical and educational experts persuaded parents to place their children in special schools which would meet their needs and would be a better place for them. In turns, “mothers accepted placement decisions as ‘expert opinion’ without appeal, reflecting how professionals exercise social control through expert authority” (Rizvi, 2017, p. 95). I can argue here that there are criticisms of the medical model.

In Landsman’s (2005) study, mothers who participated in this study believed that prejudices within society remained the biggest barriers to their child, not the disability itself. Mothers in this study seems to embrace the social model, in the sense that they believed social barriers served to create the disability; yet at the same time, they adhered to the medical model by continuing to seek intervention to mitigate the impact of a disability (Landsman, 2005), though I could say that disability is the product of both individual and social factors.

The influence of both models has resulted in differing practices in educational and medical settings and has resulted in different conditions in terms of a child’s development. Mothers are expected to balance their child-rearing life with their public activities.

3.2.6 Understandings of disability in Oman

Discussing disability in Oman, it was difficult to remain focused on Oman without looking at the bigger picture and moving to Islamic values in general to gain an understanding of disability in Islam. This helped to construct a better idea about people’s attitudes towards disability.

Oman is a conservative Arabic-Islamic state featuring a mix of tribes with different origins and adheres to Islamic values that are well cultivated in Muslim religious books. These values are reflected in daily behaviours and discourses – for example, the Arabic word “inshallah”, which means ‘if Allah/God will’, is frequently present in day-to-day language. However, this should not be perceived as having religious connotations but as a natural impact of the context in which individuals live. Likewise, the phrase ‘praise and thanks be to God’ is very common among local people in Oman. This phrase in its first meaning (gratitude) is correlated with the notion of ‘health’ and ‘normality’ as people are required, according to the teaching of Islam, to be thankful for ‘God’s grace’ of having a ‘healthy’ and ‘normal’ body. It is common to notice how this issue is constructed within society since the question first arises once a baby is born: is he/she healthy/normal? This issue of health and normality has religious and cultural dimensions and is well emphasised within the Muslim holy book. The Quran emphasised the importance of human praising and thanking God for giving them all grace. One example was of being healthy and having a good body. It was stressed in the Quran the importance of being thankful to God for the creation of a ‘perfect’ body: Say, “it is He who has produced you and made for you hearing and vision and hearts; little are grateful.’ (Surah Al-Mulk, 67:23). This makes religious people constantly thank and praise God for having a ‘healthy body’, especially when they see ill or disabled people. Some Muslims believe that God creates disabled people as a ‘reminder’ to non-disabled people of God’s grace for giving them a ‘perfect’ body. Generally, people in Oman believe in God’s will, fate, and destiny, as do many religious people; anything (good or bad) that happens to a person has been written and predestined by God and objection is forbidden, so that a person must accept matters as they are, thank God, and be patient for what they have.

There is also a connection between different religions and interference between Islam and their religion/culture in relation to how these different beliefs perceive disabled people. The idea of perceiving a disabled person as ‘God’s plague’, or test, or punishment, is constructed in other culture, signifying that disability is interpreted as punishment for one’s own sin or one’s parents; a test of faith; ‘God’s plague’; an opportunity to build character or to inspire others; an occasion for the power of God to be made manifest; a sign that one lacks faith; or simply a mysterious result of God’s will (Bazna and Hatab, 2005). However, at the same time, other cultures can differ in dealing with disabled people. For example, perceiving a disabled person as an outcome of evil spirits (Rozario, 2009) is not common in Muslim societies. In the Islamic approach, disability and differences in people are understood (AlZidjaly, 2015). However, disability as a complex phenomenon has been considered as an individual tragedy, as a socially constructed issue, and as a combination of personal and societal factors.

Looking at the social model, there was a lack of response to the global and local social changes within one social context such as Oman. Oman has a different culture and different political, economic, and religious systems and demographics from many other countries. Some of the embedded Western values (such as giving people greater freedom) may be viewed differently in Islamic cultures. Even in a country such as the UK, there are researchers who critique the social model in that it neglected the difficulties associated with experiences of individuals with learning disabilities (Rogers, 2016). Rogers described the model as ‘alien’ in relation to the experiences of people with learning disabilities and their families (Rogers, 2016: 27).

When we look at Oman form the social model perspective, we notice that some principles already exist there. For example, Oman is considered a socialist society, providing free services such as health and education for all citizens and assuming responsibilities to improve the income resources for them (see Chapter Two). However, the other principles of the social model that emphasise the empowerment and emancipation of disabled people and the issues that focus on building an accessible environment are still not met in the Omani context (AlZidjaly, 2015). There is also negligence in incorporating experiences associated with impairments, as well in recognising the impossibility of designing an environment that accommodates all disabled people. Understanding disability is also limited in providing in-depth and complex analysis in the lives of disabled people.

The cultural or religious model of disability for Oman is helpful in deconstructing and understanding beliefs towards disabled people, such as the phrase ‘praise and thanks be to God’ (AlZidjaly, 2015). I find relating aspects of politics, religion, culture, social life, and Arabic habits to be extremely important for Oman. The ‘disablist’ phrase and other phrases indeed have negative effects on disabled people’s lives. They also reinforce the notion of ‘normality’.

Generally, disabled people in Oman are experiencing challenges in receiving their civil rights and the services allocated to them by the country and, therefore, it is crucial for disabled people in Oman to receive a medical diagnosis to access services (AlFarsi, 2016; AlKindi et al., 2016). I understand that these processes can be a form of oppression when, for example, misdiagnosis or unnecessarily bureaucratic procedures happen. However, these procedures are important for detecting those disabled people. The study could explore the different models mothers use and experience when conceptualising disability.

I have presented a review of models, including medical, religious and social models, and ableism and disablism models of disabilities. The section began by presenting a discussion of the four models of disability in terms of how they are interrelated and different, in explaining what constitutes the problems of disability and how disabled people are viewed. This revealed how these models sometimes intersect with one another, although they have significant differences. It also presented disablism and ableism in terms of how they follow different paths to affect the lives of disabled people, especially in educational settings. I also gave a general overview of the disability models that helped me to develop my own conceptualisation and that were appropriate in providing an understanding of disability in Oman. The possible link to these models provided me with a good critical foundation as well as contextualising the research focus within a broader sense. I could also benefit from making links with the wider literature, based on understanding different religions' views towards disability and providing a more critical discussion on how these models of disability have an influence on the parents of disabled children. It is also suggested that mothers can ascribe to a religious-based understanding of disability and the social modes of disability at the same time.

3.3 ASD definition and nature

In this section I will concentrate on ASD in relation to the experiences of Omani mothers of children with ASD and their choices and decisions about their children’s education. ASD is also a condition that people in Oman are recently becoming aware of, as noted in Chapter two, despite its history of prevailing in the Omani community just as elsewhere.

The definition of Autism Spectrum Disorder, or ASD, has been the subject of continuous debate (Masi, et al., 2017). It has become an international concern for parents, educators, psychologists, and neurologists over several decades. This attention has resulted, for example, in debates about the accuracy of diagnoses, the sub-types and the diagnostic threshold that relates to ASD (Masi, et al., 2017). These debates have been caused by the complexity of identifying the features of each individual with ASD. For some children (and the discussion is terms of children throughout this chapter), ASD might not be evident from birth; its characteristics may not emerge until 2 or 3 years of age (Wall, 2010). The definition of ASD is that contained in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). The American Psychiatric Association places ASD in the category of neurodevelopmental disorders. This is a group of disorders that typically manifest early in development, before the child enters school. They are characterized by developmental deficits that cause impairments of personal, social, academic, or occupational functioning (APA, 2013). According to APA, (2013) these developmental disorders are easily confused with other developmental disabilities such as mental retardation, cerebral palsy, and disorders that have long-term impacts on learning, language, mobility, and self-care. ASD can sometimes be diagnosed only when the characteristics of social communication associated with excessively repetitive behaviours, restricted interests, and insistence on a routine are presented (APA, 2013).

The American Psychiatric Association, DSM-5 (2013), set the criteria for the assessment of ASD, with reassessment occurring across the developmental period, because ASD may be unstable, particularly in early childhood. According to DSM-5 (2013) there used to be three criteria to identify a child or adult with ASD. These were limited capacity in understanding and using verbal and non-verbal communication, a limited capacity to understand social conventions and the appropriate form of social interactions, and difficulties in thinking and imagination. These were called the triad of impairments, as suggested by Wing (2002, cited in Wall 2010), and may occur at different severity levels (Wall, 2010). The differences in the level of severity of ASD amongst individuals led to the use of the term ‘spectrum’ (Tissot & Evans, 2006). However, the new DSM-5, 2013, changed the definition of ASD in order to consolidate the five subcategories of ASD under one umbrella of diagnosis, including Asperger’s. In DSM-5 ASD is now defined by two characteristics: 1) persistent deficits in social communication and social interaction across multiple contexts, and 2) restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). This definition can be seen as a very medical/ableist approach.

Understanding the characteristics of children with ASD might help parents to access a wide range of services such as healthcare, rehabilitation, and education for their children with ASD. Goin-Kochel et al. (2007) reported that parents dedicated their energy, money, and time to finding support for their children with ASD. Therefore, it is important for this study to examine the different understanding of ASD as this will inform the way in which Omani mothers understand ASD and their perception of it in relation to their children with ASD. The investigation is to explore the different models of disability that mothers perceive their children’s condition

3.3.1 Theories and causes of ASD

The causes of ASD are seen as controversial because there are no clear-cut assumptions or notions to justify the causes (Faras et al. 2010; Tomiyama, et.al., 2018; Campisi, et al., 2018). The variation of understanding ASD could also be related to the different models of disability. The medical model could attribute ASD as the cause of the individuals’ impairment, which could lead parents and professionals to look for ‘cure’ or ‘treatment’ for the ‘problem’. On the other hand, the social model focuses mostly on how barriers in society and the environment surrounding an individual result in disability. In this section, some suggested theories are discussed in order to understand the factors believed to cause ASD. Biological and psychological theories will be looked at, which provide a variety of classifications and justifications in an attempt to understand the nature and causes of ASD.

Cook and Willmerdinger (2015) state that research in the area of ASD has grown significantly in recent years because of the explosion of diagnoses of the disorder. Results gained from studies conducted on twins and families have suggested that genetic liability plays a part in causing a child to have ASD (Rutter, 2005a, 2005b). However, these studies failed to identify any single gene trait that is passed from a parent to a child that would cause ASD (Rutter, 2005a). In addition, there has been some medical research to suggest that several genes could be responsible for ASD's manifestation (Newschaffer, et. al., 2007). Another suggested cause of ASD is abnormality in brain size, structure, and functioning (McDonald, 2014). According to others, for example Smallwood et al. (2016), ASD is likely may also be caused by environmental factors. According to Smallwood et al. (2016), research has been carried out on children's head circumference, with measurements being taken at birth and at ages between 6 and 14 months. The findings proposed that increased head growth in infancy could be a possible marker of ASD (Myles, et. al., 2007).

The literature has identified another possible cause of ASD: brain circuit dysfunction (McDonald, 2014; Sasson, 2006). Researchers have found that there can be a problem in the temporal lobe of the cerebrum that affects activation levels differently to the case for typical individuals. Indeed, the result of this problem can be difficulty in processing faces and social cognition. On the other hand, other researchers such as Sasson, (2006); Ha, et al. (2015) have stated that brain cells that are responsible for thought, language, and reasoning may be less efficient in the way they communicate with each other for people with ASD.

In conjunction with the possible biological and hereditary causes of ASD, any prenatal exposure to things such as toxins, as well as birth defects, pregnancy infections, or birth trauma, have been found to possibly increase the risk of the child having ASD (Smallwood, et al., 2016). Diet and preservatives in vaccines are also considered by some to play a role. Greenspan and Wieder (2006) recommend that considering cumulative risk and multiple pathway models is a more flexible and comprehensive approach to understanding ASD causation. This framework acknowledges the interaction between both genetic and prenatal factors that may make a child vulnerable to developing ASD when confronted with environmental stimuli. Adopting this flexible approach might lead to developing a broader understanding of all the surrounding causes and factors associated with ASD (Greenspan & Wieder, 2006).

Therefore, there is no clear-cut understanding of ASD, and for this study it was vital to look in brief at the causes of ASD in order to understand the children's condition that might have an impact on the experiences and feelings of mothers of children with ASD, which is the subject of this study. As soon as parents, and specifically mothers, receive a diagnosis of ASD for their children, they start investigating the causes of their child's condition, and, according to Hodgetts et al. (2017), this affects those parents' wellbeing. Further, it has been noted by Reed et al. (2016) that a child's outcomes are closely associated with their parents' wellbeing. Wellbeing and mothering a child with ASD will be discussed in detail section (3.4) below, which considers mothers' emotional experiences and how they are driven to look for causes of their children's disorder. The impact of this understanding can be caused from a medical perspective (as was discussed in section 3.2). The deficit is within the children which need parents to consider the causes to it.

3.3.2 Diagnosis and Prevalence

The recognition and understanding of ASD have expanded significantly over the last three decades (Bent, Barbaro, & Dissanayake 2017; Lord & Bishop, 2010; Randall et al., 2016). ASD prevalence estimates vary over time, with the more recent studies showing higher prevalence levels of ASD than research conducted in the past. Historically, prevalence estimates have also been affected by ASD's varying definitions. Carpenter et al. (2016) stated that prevalence of ASD according to the DSM-5 criteria has been higher than that calculated when applying the DSM-IV criteria for the same population. Prevalence estimates are also affected by the methodology used to ascertain this research study “screenings and in-person diagnostic confirmation methodology have yielded prevalence estimates that are greater than administrative or surveillance estimates” (Carpenter et al., 2016: p. 396).

The literature suggests several diagnostic criteria for diagnosing ASD. The DSM-5 (APA, 2013) and the International Classification of Disease, Tenth Edition version (ICD-10) are the most commonly used diagnostics. The two provide a comprehensive list of criteria, including symptoms for diagnosis and age of onset, that has provided a structured framework for the use of clinicians attempting to diagnose and assess ASD. According to APA, (2013), specifiers such as intellectual disability and language impairment can also accompany the diagnosis of ASD. This means that the clinicians can provide a diagnosis that clearly highlights areas of support for each individual (APA, 2013).

The earlier ASD is identified, the better the services that can be provided for children with ASD (Hodgetts et al., 2017). The concerns remain about the prospect of providing such services for an increasing number of families impacted by ASD (Matson et al., 2008; Rajendran & Mitchell, 2007; Stahmer, 2007; Shattuck & Grosse, 2007, Kurth, et al., 2016). The increase in the prevalence of ASD strains health, education, and community services (Hodgetts et al., 2017). In addition, the families of children with ASD can find accessing such services problematic and can find that their needs are not met (Hodgetts et al., 2017). This, consequently, may affect families’ experiences and feelings about the availability and the quality of services provided in their country. As was mentioned in Chapter two, the diagnosis of ASD is part of the health services provided in Oman that parents of children with ASD are struggling to access (Al-Farsi, O., 2016). The next section will be about education and social services for children with ASD, how such services appear, and the relevant terminology related to them.

3.4 Parents' educational preferences for their children with ASD

According to Starr et al. (2006) in Western countries such as the USA, the UK, Australia, and European countries, some students with ASD have been educated in mainstream classrooms, with sometimes withdrawal for part of the day. Children with severe disabilities such as severe ASD have typically been educated in full-time special education settings. There has been a movement towards parents wanting their children with disabilities to be included in mainstream education (Starr, et al., 2006).

There has been a continuous debate amongst educators, professionals, and parents as to whether children with ASD have the right to be educated in mainstream schools (Rieser 2001; Lindsay, 2003). This argument has emerged from medical and social lens. Rieser (2001) argues that it is a child's right to be included in mainstream schools and stated that schools should accept them regardless of their special education needs. However, Lindsay (2003) and Low (2007) argue that if the ultimate aim is to meet those children's needs, then the option of specialist school education should be considered. This latter argument is that what is best for the child is more important than just including them in mainstream schools. Lindsey (2003), and Wedell, (2008) suggested that there should be a flexible educational system that meets the different needs of all learners, Rogers (2011) extends this by pointing out the need for supportive and partnership work as important and necessary for practice within the health, education and social work.

The work of Rizvi (2018) who investigated British-Pakistani mothers of children with special education needs in UK experience the placement decision- making process and the relationship between their notions of inclusion and different placement settings. She found that mothers generally preferred special schools that have plans for eventual mainstream integration and that these schools had the least disabling and the least medicalized setting. Mothers also wanted special schools to provide meaningful progression for their children with disability into adulthood, by offering mainstream transitions (Rizvi, 2018). However, the research reveals that mothers' final placement setting did not always reflect their original parental preferences, nor did current placement settings exactly match maternal expectation of the mothers' ideal school for their children.

Some parents choose to keep their children at home and teach them as an alternative to formal classroom schooling. This was shown in a study by Parsons and Lewis (2010) who surveyed 562 parents in UK who preferred to homeschool their children with special education needs (the greatest proportion of whom were parents of children with ASD). They found that the reason for home education being preferred was either the parents' perception that the school did not provide a suitable programme for their children or that in other educational settings particular negative experiences, such as bullying, were encountered by the child. Parsons and Lewis (2010) also found that homeschooling parents were concerned about insufficient academic progress and a failure by school-teachers and administrators to understand their children's disability. The study found that parents of children choosing to home educate their children with disabilities might find difficulties, such as limited resources and support from educational authorities. Once they choose to home educate, they need to provide all the educational resources for their children (Parsons & Lewis, 2010). They seek support from a variety of different agencies, especially parent home education networks. Machalicek et al. (2007), in their review of twenty-six studies, found that parents seem to use one-to-one strategies with their child and individualize instructions according to their child's interests, social needs, and pace of learning (Machalicek et al., 2007). It has been noted that the individuality and flexibility in teaching children with disabilities results in the improved social and academic progress of the children (Machalicek et al., 2007).

A qualitative study conducted by Kidd and Kaczmarek (2010) investigated ten Australian mothers' experiences of home educating children with ASD. The study found that the children's academic learning and psychological wellbeing benefitted from an individualized, modified, and flexible approach to education. The study findings were consistent with those found in research conducted by Machalicek et al. (2007) and Parsons and Lewis (2010). According to Hurlbutt, (2011), some parents think that home is the place where a child's needs are served best and they feel that they can provide the same opportunities and experiences for their children as a school can. The mothers in Kidd and Kaczmarek's (2010) study reported that the regular school environment was a "considerable source of anxiety for their child" (p. 270). They also reported the feeling of stress from school being carried over into the home by the child as a result of the difficulties they encounter at school (Kidd & Kaczmarek, 2010). In contrast, when mothers decided to home educate their children with ASD, they reported a decline in their stress and stress in the family (Kidd & Kaczmarek, 2010). Though mothers have expressed positive feelings about home educating their children with ASD, such as a sense of empowerment through their role as educator, they have also voiced a lack of educational, social, and financial support. These feelings have been recorded in a number of studies, for example Machalicek et al. (2007), Zweers et al., (2019) and Parsons and Lewis, (2010). Since this current study is looking at mothers' experiences in choosing education for their children with ASD, it was essential to explore the literature on the different preferences that parents might have regarding educating their children with ASD. There has been some research into the area of parents' experiences with the provisions for their children with ASD, but very little research into the mothers' experiences specifically about choosing education for their children with ASD.

From the present researcher's own experience, and knowledge based on an exploration of the educational system, the education service for children with special needs has been lagging behind other developments in the country. The question remains as to whether there is a gap in accessing relevant services in the country. There are still unresearched areas as to where children with ASD are educated, what parents' preferences are, and whether they choose to home school (see Section 2.6).

3.5 Parents' experiences with children with ASD

In this section, literature is explored that documents the experiences of mothers of children with ASD. Three parts of these experiences will be explored: the parents' emotional responses to the diagnosis, their emotional difficulties, and their coping strategies.

A number of studies (for example, Landsman, 1998, Rivard et al., 2014; Moh and Magiati, 2012; Reed et al., 2016; DePape & Lindsay, 2015, Al Bloushi, 2019) have explored parents' emotional responses to their child's diagnosis of ASD and they have identified a wide range of emotions. For example, stress in the parents of children with ASD has been found to commence the moment their child is diagnosed with ASD (Rivard et al., 2014). Moh & Magiati (2012) report that late diagnosis increases the level of parental stress, because they might have missed the opportunity to implement early interventions that, arguably, may have been needed to develop their child's skills. A feeling of relief was noted in DePape & Lindsay's, research (2015) because the diagnosis identified a name for the behaviour of the child, which the parents had previously just described as 'different' or 'odd'. The feeling of relief was particularly because of the long, difficult, and frustrating process of diagnosis. The study by Reed et al. (2016) noted that the speed and coherence of the diagnosis reduced mothers' anxiety but increased the overall level of parental stress. Shock, sadness, disappointment, and denial were reported in other studies (for example, those of Ludlow, Skelly, & Rohleder, 2012 and Corcoran, 2015, Wong et al., 2012). The feelings of shock and disappointment were associated with the "never-ending" challenges that their children faced (Ludlow, et al., 2012). The feeling of loss was reported because of being unprepared to contend with the experiences or the grief of having lost the "real child" the parents had waited for (Fernandez-Alcantara et al., 2016). A study of parents conducted by Poslawsky et al. (2014) in the Netherlands with 77 participants (90% of whom were mothers) found that parents of children with ASD showed acceptance of their child's recent diagnosis. This response was reported to be "associated with the severity of the child's ASD" (Poslawsky et al., 2014: p. 303).

Some of these findings are reflected in studies with regards parenting of children with a range of disabilities. Rogers (2011) reports on conflict of emotions when considering taking diagnostic tests, the emotional angst mothers feel, including “disappointment” and “heartbreak” (p. 138). Mothers’ feeling could be also related to lack of knowledge about disability and accompanied by the sense of fear about “the other” particularly there is a deep parental investment in cultural ideologies of perfect children and ‘good parents’ (Landsman, 1998). Then they adapt, adjust and develop a range of skills as they mediate and negotiate the world on behalf of their children.

Al Bloushi (2019) completed a literature synthesis of articles exploring the experiences and perceptions of mothers caring for a child with cerebral palsy. Thematic analysis of the findings of her included studies showed that a number of the studies discussed “reactions to the news of diagnosis” (p. 62) exploring emotional reactions, trauma, denial and shame. Rogers (2007) outlines the “loss of the expected child” and associated issues of “shock”, “denial” and disappointment” (p. 42).

In addition to stress at the diagnosis stage, parents experience difficulties and stress for other reasons. It has been documented that stress is associated with the severity of a child’s ASD symptoms and behaviour problems (Davis & Carter, 2008; Levin & Scher, 2016; Reed et al., 2016; Tekinarslan, 2018). In a study in Israel conducted Levin & Scher (2016), mothers of children with ASD experienced stress caused by sleep problems in their children. Sleep problems were also studied and reported by Al-Farsi, (2016). The study of Levin & Scher (2016) indicated that sleep problems were the main source of maternal stress, more than the symptoms’ severity. In Reed et al.’s study (2016), many of the 158 mothers of children with ASD were found to display a high level of stress and this, in consequence, affected parental health and the child. Tekinarslan (2018) reported that high levels of stress in mothers was found to be associated with the severity of child’s impairment, the behavioural problems of the child, a lack of social support, a lack of information and guidance for childcare, financial constraints, and the perception of social stigma.

Other research (Benson, 2018; Tomeny et al. 2016; Cianfoglione, 2015; Zaidman-Zait et al., 2017; Tahmassian, 2011, Dillenburger, et al., 2010) has indicated higher levels of stress and poorer mental health in parents of children with ASD than parents of children with other disabilities. The literature has also pointed that the higher levels of maternal stress and unhappiness due to having a child with disability (Landsman, 1998). From a medical understanding, mothers experience delusion or grief as they were unable to produce children that were considered as 'normal'. They experienced the feeling of fear about 'the other', as there is a deep understanding in cultural ideologies of having 'perfect babies' and 'being good parents' (Landsman, 1998).

Benson's (2018) findings report on a number of mothers of children with ASD over a period of time from 2006-2016 in USA. The number of mothers varied because the assessment was conducted five times over the period 110 (Time 1), 107 (Time 2), 98 (Time 3), 59 (Time 4), and 82 (Time 5). The findings indicated a significant decline in the mothers' health as well as a rise in depression. Tomeny et al. (2016) conducted research in USA which reported that not only did the mothers of children with ASD face emotional and behavioural difficulties, but also that other family members were affected, such as typically developing siblings. The more severe the ASD 'symptoms' in the child, the more difficulties were reported in the study. Being the mother of a child with developmental difficulties has been demonstrated to affect parents' wellbeing (Cianfoglione, 2015). Parents of children with ASD appear to be vulnerable to higher levels of stress (Blacher & McIntyre, 2006) and depression than parents of children with other disabilities. Knight (2012) also emphasizes that the expectations that the society expect parents of children with disability to play are disempowering them. The parents are expected to raise a child in a society that devalue their identity as parents (Knight, 2012).

Mothers of children with ASD reported a negative impact and poor wellbeing during their children's preschool years (Eisenhower, Baker & Blachers, 2005). Smith et al. (2008), when comparing mothers of toddlers and mothers of adolescents, stated that mothers generally showed signs of significant distress and anger associated with the frustration of parenting an individual with ASD. According to Zaidman-Zait et al. (2017), the stress is created by a mismatch between the parents' perceived expectations about parenting and the personal and social resources available to meet these expectations. The longitudinal study of mothers by Zaidman-Zait et al., (2017) reported a clear relationship between parents' stress and children's characteristics, as well as parents' personal and social resources. Successful coping strategies implemented by parents can lead to a lower level of stress, which strongly recommends individualized and appropriate support services for such parents to help them cope and deal with stress (Smith et al., 2008; Zaidman-Zait et al., 2017). Other factors might be related to children's behaviour, sleep problems, and remarks from other people regarding their children's behaviour (Huang et al., 2014).

Results from Dieleman et al.'s (2019) study of the sources of daily parenting among mothers of children with ASD in Belgium showed that stress varies across parents as well as across days, so effective parenting strategies for mothers of children with ASD need to consider mother and child's needs. Ekas et al. (2015, 2016) found that family cohesion was a significant factor in positive adjustment and would help mothers of children with ASD to adjust and adapt their lives. There are other contributors to a better life, such as optimism, the receipt of benefits, and social support, but family cohesion and family relationships were found by Hodgetts et al. (2017) to increase maternal wellbeing and prosperity as well as cooperation between mothers and their family members which is crucial for improving mothers' wellbeing. Hodgetts et al. (2017) interestingly found that maternal psychological wellbeing was positively related with the perceived continuity and quality of services. The more services that were provided for both children and their families, the better the wellbeing of the mothers.

Al Bloushi's (2019) literature synthesis revealed a number of studies explored mothers' level of stress (including outcomes such as anxiety and depression) after diagnosis, labeling this theme "emotional difficulties" (p. 63). Her cited studies found that these mothers tended to have lower satisfaction with life and higher levels of anxiety and depression when compared to other mothers.

While these findings were related specifically to mothers of children with Cerebral Palsy, the literature above shows similar findings for parents of mothers with ASD. Rogers (2007) describes parents experiences of stress, depression and anxiety, and the impact these have on the parent’s mental health.

Al Bloushi’s (2019) next sub theme in “emotional experiences” reflects on findings related to “coping strategies”, namely finding information seeking, acceptance, and support. Rogers (2007) notes how support, particularly social support (from a range of people, including disability support groups), has a positive effect of mental health/wellbeing. With regards coping strategies of parents of children with ASD, there are two studies (DePape & Lindsay, 2015; Benson, 2018) which have explored the coping strategies used by mothers or parents of children with ASD to cope with their emotions at the time of the diagnosis. These studies found that parents frequently used strategies such as seeking information, seeking cooperation with family members, and seeking social support and religious support. Obtaining adequate information about their child’s condition and how to cope with stressful situations were perceived by parents in these studies as essential factors to cope with the child’s condition. There are other strategies reported in DePape and Lindsay (2015) that had a good impact on parental mental health. Being optimistic about the child’s future and accepting the situation helped parents to cope well with their child’s condition. Being positive about taking care of a child with ASD enabled them to find meaning in caring for their child and to cope with the stress. Another coping strategy that parents reported is depending on relationships with family members, family cohesion, and cooperation within the family. This strategy enables parents to cope with the stresses associated with care for their child (Ekas et al., 2016). The feeling of being together and cooperating with each other provided them with better family functioning. The help that parents receive from family and friends helps in reducing the negativity of the situation and promotes mothers’ self-esteem (Halstead, Griffith & Hasting, 2018). Another strategy that has been found to be effective is spiritual and religious support, which has been found to give mothers strength and courage to cope with the stress of caring for a child with ASD (Halstead et al., 2018). Mothers perceived themselves as being special and chosen by God to be the mother of a disabled child (Halstead et al., 2018).

Hastings et al. (2005) explained that many families can succeed in raising a child with ASD because they are either successful in using strategies to cope or to have significant investment in the development of their child. In their research conducted on the biological mothers and fathers of children with ASD, Hastings et al. (2005) found there were four coping mechanisms related to parents raising a child with ASD. These are active-avoidance coping strategies, positive problem-focused coping strategies, emotion-focused coping strategies, and religious coping strategies. The active-avoidance approach was found not to be helpful in enabling parents to cope with the stress, and parents reported more stress and mental health issues. The positive problem-focused approach may help parents to cope with the stress of raising a child with ASD.

The experience of mothering a child with disability is complex and contradicting at a number of levels which extend over and above those mothers of non-disabled children (Ryan & Runswick-Cole, 2008, Rogers, 2007). It is important to understand the factors affecting the wellbeing of parents raising a child with ASD because low levels of parental wellbeing could lead to a negative impact on the child's development and also have a negative impact upon the parents themselves (Reed et al., 2016; Halstead et al., 2018). Stress and depression in parents impact the outcomes of children with ASD, including language and cognitive problems, social interaction difficulties, and behavioural problems. Parental anxiety has also been associated with higher levels of behaviour problems in children with ASD (Reed et al., 2016). Therefore, investigating the studies examined in this section is important to understanding the mother of a child with ASD experiences, perceptions, and feelings.

3.6 Parents' choices and decisions for the education of their children with ASD

In this section, the focus will be on parents' and mothers' choices and decisions about the education of their children with ASD, as well as their experiences in accessing available services.

3.6.1 Decision-making for educational placement

The decision process of finding a placement for a child with ASD has been found to be highly emotionally stressful for parents (Tissot & Evans, 2006; Swick & Hooks, 2005). According to Parsons, Lewis and Ellins (2009), parents of children with ASD experienced more stress in finding placement, and more intense stress, than parents of children with other disabilities. They find the experiences of decision making for their children with ASD challenging because they are the key agents in their children's progress and success (Sandall, McLean & Smith, 2000). Garfinkle and Schwarts (2002) describe rational choice theory, which assumes that people are rational decision-makers who have well-ordered preferences and complete information regarding the gains and losses associated with each alternative. In addition, Macy (2006) reported that in the process of decision-making, parents have the ability to compare alternatives, preferences and to choose the place, the time, and the plan that would meet their child's needs.

Parents are regarded as full partners in their children's educational process (Duncan, 2003). They are considered as consumers of educational services attempting to make costs-versus-benefits calculations and weighing the probabilities of success for the various options that they could pursue (Bosetti, 2004). However, the reality entails complex factors, such as the process of choosing a school for the child is itself social (Coleman, 1988), moving through different stages/types of expectations (Rogers, 2007) and is consequently a complex and multifaceted affair (Rogers, 2007). Therefore, social networks can provide individuals with access to relevant and valuable information regarding their choices and help them to make the most well-informed decisions. Individuals can also attempt to maintain control over the choice-making situation, which will reduce their sense of stress (Bosetti, 2004). Parents also depend on their personal values and subjective expectations of the educational framework, and on their social and professional networks, to collect information about the schools (Bosetti, 2004). In this way, it is argued, they will be able to make informed decisions regarding their child's education.

Foot et al. (2000) recommend that parents' educational pre-school decisions can be predicted based on the theory of planned behaviour. Accordingly, parents' preferences, knowledge, beliefs, and expectations make up the final decision-making process. Behavioural beliefs, normative beliefs, and beliefs about opportunities and resources inform parents' choice. Behavioural beliefs include parents' knowledge, values, and preferences regarding the characteristics of good educational provision (Foot et al., 2000). These characteristics pertain to care and safety, educational goals, the meeting of children's needs, convenience, knowledge of the different provisions available, and so on. Another source is the parents' beliefs about the opportunities and resources available that would enable them to make the right choice; this gives the parents a sense of control over the choices they make (Foot et al., 2000).

When deciding on educational provision, parents usually require a range of information about the parts of the provision that relate to the education of their child (Rizvi, 2018; Rabba, 2019; Macy, 2006). Being repeatedly exposed to problems in the decision-making process (Macy, 2006) will help parents to reach decisions in an informed way. Parents constantly seek more information about the various aspects of the process through various social-exchange situations and activities. Finding out about educational provision options can be time-consuming and may have financial implications and create emotional stress, resulting in decision fatigue in the parents (Rabba, 2019; Vohs et al., 2014). Vohs et al. (2014) argue that the more choices parents have, the more stressful the situation is. This is because parents need to consider more alternatives and more resources and therefore more energy is consumed, resulting in a process that creates a burden and subsequently leads to impairments in self-regulation, resulting in the breakdown of self-control and eventually in ego depletion. Furthermore, the complexities of the human environment and the limitations of human information processing mean that people are mostly motivated by the need to satisfy the minimum requirements rather than to maximize reward. To be satisfied is to pursue the good-enough option, the acceptable one that does not demand any extensive use of energy and time (Garfinkle & Schwarts, 2002). Some researches suggest that choice situations becomes risky when there are various options to consider (Garfinkle & Schwarts, 2002; Connolly & Zeelenberg, 2002, Rodger et al., 2008). This makes the process more confusing and may result in dissatisfaction with outcomes obtained in post-decision situations, thus leading to a negative emotional response (Rogers, 2007). However, people experiencing a situation in which the choice is limited to fewer options express greater satisfaction and pleasure with the choices they make (Garfinkle & Schwarts, 2002). When the choice situation involves varied options, it might also result in disengagement and an almost arbitrary choice being made in order to complete the process, resulting in regret and loss aversion. The argument here is that when the options are few, people tend to blame the situation for disappointing outcomes; but when a situation offers many options, people tend to blame themselves and their own actions, bringing depression and a sense of personal failure (Connolly & Zeelenberg, 2002). The act of deciding on educational provision is an uncertain, multi-faceted, and sometimes risky activity (Rogers, 2007), because inclusion within the mainstream might lead the child of not being able to cope with the 'real' environment of mainstream. Therefore, parents are expected to make rational choices regarding the interests and the characteristics of their children with ASD, thus they are supposed to make conscious considerations among alternatives, weighing information about currently available options, and selecting the option that seems to be the most promising.

To sum up, the experiences of having a child with ASD, a lack of information about procedures, and uncertainty about the best educational provisions for their child with ASD make the decision-making process for parents a difficult one where no single choice appears to be the absolute best option. The literature I have reviewed here is not specifically about ASD, but I am applying it, because it seems highly relevant. In the context of a country like Oman, the options are limited (as mentioned in Chapter two). Therefore, parents' choices and decisions may be affected by many other aspects that have not been mentioned in the previous literature in Oman, such availability, access and quality of services, and other influences that seem to affect their choices such as family and community support.

3.6.2 Educational provision for children with ASD

Finding a school or a centre that can accommodate their children is considered a challenging time for parents of children with ASD, as it brings new demands and challenges (Parsons, Lewis, & Ellins, 2009; Quintero & McIntyre, 2011; Connolly & Gersch, 2016). The difficulty can include concerns about stigmatization and how the child will cope with the school environment. Ryan and Runswick-Cole (2008) argue that mothers of children with disability experience a form of disablism emerging from medical model of disability (see section 3.2 about disability models) which focus on the burden of having a child with disability. The disablism occur through discrimination directed at the children in both attitudes and action (Ryan & Runswick-Cole, 2008). There are also the 'pathways' parents go through – beginning with hoping for, or even expecting, a mainstream education for their child; the families' experiences of mainstream and/or special education; and the impact of those experiences (Rogers, 2007).

From a series of interviews with mothers of children with ASD in Australia, Lilley (2015) found that mothers experience stigma from professionals towards their children with ASD and have witnessed a tendency for their children to be excluded from educational settings because of their condition. Connolly and Gresch (2016) examined parental perspectives and experiences regarding children with ASD starting at school. Stigma from professionals towards children with ASD was a concern of many parents in the study. Their concerns were because they felt that this stigmatization might lead to social exclusion by the children's peers and their families. Parents' concerns also included the worry that some professionals either overestimate children with ASD's coping abilities or underestimate the potential of less verbal children.

Participants in Connolly and Gersch's study (2016) described their fears that their children would be stigmatized by peers and other parents, which may lead to social exclusion. They also feared that labeling has the power to change how people view their children's behaviour. Consequently, finding a place that might meet their children's needs is a source of anxiety for many parents of children with ASD (Connolly & Gersch, 2016). It was also reported that there is a vital need for communication between school professionals and parents to facilitate preparation for the transition into school. There is an essential need for communication between preschool teachers and school teachers to support children with ASD in the transition stage. Many parents expressed the difficulty in their struggle to find a suitable school for their children. The study by Connolly and Gersch (2016) echoed a previous study by Parsons et al. (2009), which also reported concerns from the parents of children with ASD about the appropriateness of the schools their children were attending. Most of the parents in the study expressed their concerns regarding the schools their children were starting in. These concerns seemed to be related to parents' concerns about school safety, social inclusion, and bullying.

Previous research has explored the different aspects of parents' perceptions about the education of their children (Brewin, Renwick & Fudge Schormans, 2008; Renty & Roeyers, 2006; Rogers, 2007, Stoner et al, 2005; Whitaker, 2007, Slade et al., 2018). It has shown that there is variation in parents' levels of satisfaction regarding the education of children with ASD (Rogers, 2007). Children with a variety of disabilities as well as children with ASD were included in the research conducted by Parsons and Lewis (2010). Other studies have also explored the perceptions of parents with children with ASD specifically (Brewin, Renwick & Fudge Schormans, 2008; Renty & Roeyers, 2006; Stoner et al, 2005, Whitaker, 2007) or parents of children with ASD compared to parents of children with other disabilities (Parsons, Lewis & Ellins, 2009). Results in Parsons, Lewis and Ellins (2009) showed the views of parents of children with ASD versus non-ASD, which showed more similarities than differences in relation to the positive aspects of provision as well as children's improvements. The research reported that the majority of the parents were satisfied with their child's education programmes (Parsons, Lewis & Ellins, 2009).

Starr and Foy (2012) also surveyed 144 parents about their satisfaction with the education their children were receiving. They stated that regardless of changes in legislation and policy, which have increased the role of parents as school advocates and partners, many parents feel that their children's needs are not being met within the school system. These studies found that a slight majority of parents are satisfied with their children's education; however, many others expressed dissatisfaction. Starr and Foy (2012) identified three main elements that shaped parents' perceptions of educational programs for children with ASD. These are the teachers' ability to manage behaviour, the teachers' knowledge and understanding of ASD, and the quality of collaboration and communication. Parents participated in the survey of Starr & Foy (2012) whose children were at that time enrolled in a publicly funded school system and were diagnosed with ASD. Many of them were dissatisfied with the education system and felt that it was not meeting the needs of their children, due to a lack of knowledge about ASD among school staff and administrators, because of a lack of training and professional development about ASD.

Many parents in the Starr and Foy (2012) study expressed the view that their children needed fully trained experts, speech therapy, increased educational assistant time, the incorporation of technology into their education, and the integration of social skills training and sensory training. The parents hoped to see their children's needs for a high level of independence and happiness met by 1) the completion of a certain level of education, and 2) the acquisition of numerous other skills such as communication skills, self-help skills, and the ability to establish social relationships.

Starr, et al. (2006) studied parents of children with ASD, Downs Syndrome, and other learning disabilities and examined their perceptions of the education of their children. The study found that parents of children in all groups tended to feel that teachers generally were not able to deal with their children's challenging behaviour. The results identified key factors contributing to parents' satisfaction levels, such as having knowledgeable and supportive staff, feeling that they as parents are part of the decision-making process, and having teachers who are willing to learn about the disability and adapt their teaching accordingly (Starr, et al., 2006).

3.6.3 Parents’ involvement in the education of their children with ASD

Parents’ role in their children’s education has been well documented as crucial in order for children to achieve life and academic skills and eventually become independent citizens (Stoner & Angell, 2005), Families and school professionals may play an equally active role in shaping the educational experiences of children with disabilities. According to Zablotsky, Boswell and Smith, (2017), parental involvement is a complex issue that has affordances and drawbacks, as parents might be facilitators of or barriers to the education of children with ASD. They may have too much interference in the educational process or they may work cooperatively with the professionals (Zablotsky, Boswell & Smith, 2017).

Stoner and Angell (2005) conducted a study of eight parents of four children in a Midwestern city in USA with a population of approximately 150,000. They could identify four main roles that parents played as they monitored their children’s educational programmes, and these roles described their strategies of interaction with school professionals. Though the study included fathers and mothers of children with ASD, the findings found that the roles of mothers were more active than those of fathers. There were four main roles that parents and especially mothers played in the education of their children: negotiator, monitor, supporter, and advocate. Stoner and Angell (2005) describe them as follows:

- The negotiator role manifests itself in the way that parents seek services that may support the needs of their children. Parents negotiate and discuss the structure of programmes that their children might need. Parents learn how to negotiate over time, as they gain an understanding of how to approach educational professionals in a way that ensures the success of their influence.
- The monitor role manifests itself in the way that parents check the quality and content of their children’s education programmes on an ongoing

basis, either formally or informally. Formal monitoring occurs at scheduled, regular events, such as in an Individual Education Programme (IEP), teacher-parent conferences, and so on. Informal monitoring by parents usually involves going through children's notebooks, assisting in classrooms and schools, or monitoring changes in behavior.

- The supporter role is fulfilled in the way that parents encourage their children's teacher by either providing direct assistance such as producing classroom materials or purchasing items for the classroom and reinforcing classroom intervention strategies.
- The advocate role is reflected in the way that parents supplement and promote activities related to ASD.

In addition, Dauber and Epstein (1993) also described parents' roles as being those of teachers, supporters of school activities, advocates, decision-makers, volunteers, homework directors, and collaborators. In general, Stoner and Angell (2005) found that parents' trust in their children's education professionals increased when they perceived these professionals as competent, having the best interests of children at the centre of their decisions, and keeping their word. Parents sought a strong bond of trust with education professionals, because they felt that such a relationship would benefit their children.

The work of Sousa (2011) also reported the different roles parents adopt. She argues that parents not only act as caregivers, advocates, therapist and partitioners for their children, they also waged the battle against social and political forces to gain medical and educational interventions for their children. Parents' works comprise the development and use of many forms of knowledge and expertise including their emotional knowledge that parents harness trajectory of care. They are converting their care of their child and hope for the future into action (Sousa, 2011). Mothers overcome fears of not loving or understanding their children to developing new knowledge and skills that can support their children's development.

Parents' participation in the education of their children with ASD has been acknowledged in the literature as resulting in positive child outcomes and improved skills (Benson, Karlof & Seperstein, 2008). Parents' involvement is considered to be a crucial practice in the education of children with ASD and emphasizes the fact that parents play an important role in supporting their child's education (Nahmias & Mandell, 2014). Parents' experiences are also regarded as having an essential role in supporting their children's educational progress because they are the first to recognize the early signs of the condition (Dobbins & Abbott, 2010; Nahmias & Mandell, 2014).

Parental involvement can take different forms, such as home-based or school-based involvement. Home-based involvement can be unstructured but effective, with parents using everyday activities, the home, and the community as a natural setting to support their children's learning and development (Dunst et al., 2011). School-based involvement can concentrate more on parents volunteering in their children's classroom, communicating with teachers formally or informally, and attending meetings and workshops (Benson, Karlof & Seperstein, 2008). Research suggests that the form that parents' involvement in children with ASD's education takes is determined by several factors: the severity of the problematic behaviour exhibited by the child with ASD; the time and energy of parents; family resources (socioeconomics and social support); and school characteristics (Benson, Karlof & Seperstein, 2008). Some children with problems in their behaviour hinder their families from participating in educational programmes, because families face difficulties and experience high levels of stress when raising a child with ASD, which problematic behaviour exacerbates (Benson, 2006; Witwer & Lecavalier 2008). Research also suggests that parental involvement is hindered when children lack functional language skills and are unable to maintain ongoing social communication or interaction, while there is greater participation from parents of children who exhibit prosocial behaviours (Kasari & Sigman, 1997 and Benson, Karlof & Seperstein, 2008). Employed parents struggle to find the time and energy to support and participate in the education of their children with disabilities (Rogers, 2007). Research indicates that working mothers, in particular, face major difficulty in balancing family and work commitments (Freedman et al., 1995). Benson, Karlof and Seperstein (2008) surveyed and interviewed 95 mothers about their involvement in the education of their children with ASD who were receiving public schooling. They found that mothers “simply do not have time or energy to devote to assisting their child educationally” (p. 58). The research also found that caring for several children with disabilities places extensive demands on families because it exerts a negative effect on the mothers’ ability to participate in the children’s home-based activities.

Parents’ socioeconomic resources and the social support that they receive affects their involvement in their children’s education (Dauber & Epstein, 1993; Turner and Turner, 1999, Rogers, 2007). Another factor affecting parents’ involvement in the education of their children with ASD is school characteristics: the more schools encourage, support and provide opportunities for parents, the more parents are involved (Hoover-Dempsey et al., 2005; Benson, Karlof & Seperstein, 2008). Schools might invite parents to volunteer in or observe their children’s classrooms, or they may offer parent training and parental consultation to develop greater participation in the children’s learning. The relationships that parents of children with ASD have with their children’s schools was examined by Lareau (1999). Lareau (1999), who found that working-class parents were less likely than middle-class parents to get involved in their children’s education, and if they did, it was generally in non-academic activities. According to research papers conducted by Benson, Karlof and Seperstein, (2008), parents from working-class backgrounds tend more to think that academic matters should be left to teachers, while parents of other classes consider themselves as the experts in educating their child with ASD.

Parents of children with disabilities reported high level of involvement in their children’s education and that their caring work goes beyond the ordinary caring role of a mother or a father (Rogers, 2007). The level of parents’ involvement in the education of their children with ASD seems to depend on three key factors (Hoover-Dempsey et al., 2010). The first is the parents’ concepts about what it means to be a parent and their motivation to help the child succeed. The second is how the parents regard invitations to get involved and the opportunities offered by educational systems. These invitations usually represent the social norms and values applied within school systems associated with parental involvement. The third factor is the parents' personal life contextual variables, including family culture and circumstances, the parents' perceptions of their personal skills and knowledge about ASD, and the time and energy they can afford (Hoover-Dempsey & Sadler, 1997; Hoover-Dempsey et al., 2005). These aspects reflect parents' type, level of involvement, and their contribution to their children's success (Hoover-Dempsey et al., 2005).

The roles taken by parents to support their children's success in school learning activities can be supported and enabled by teachers via various collaborative efforts (Kroeger & Lash 2011). However, this does not sufficiently specify the teachers' role as being one that includes gaining partnership with parents. Furthermore, the issue of the educational system's dominance can be raised, because teachers do not sufficiently account for the value of the experiences of parents, and they are likely to misinterpret parents' motives regarding their involvement in their children's education (Kroeger & Lash 2011). Consequently, the value of a teacher-parent partnership can dissolve in practice. However, when teachers learn to appreciate parents' individual and unique perspectives of their role in their children's education, partnership can succeed. This appreciation can lead parents to offer knowledge and expertise rather than act as obstacles who need to be more informed themselves (Cairney, 2000).

3.6.4 Challenges in educating children with ASD

Parental involvement has been considered either as peripheral to children's education or as an obstacle (Stoner et al., 2005). According to Stoner et al. (2005) professionals can approach teaching a child with ASD via an impact-based approach, leading them to focus more on the disability than on the individual. Parents face many challenges in educating their children with ASD, which start as they notice their slow progress. Challenges include the following: a) they struggle to obtain a diagnosis for their child; b) they have to fight to get services for their child; c) there is a lack of collaboration between parents and professionals; and d) there is inadequate service delivery (Stoner et al., 2005). The challenges that parents encounter when seeking services for their children with disability was well documented in literature (Stoner et al., 2005 Midence & O'Neill, 1999; Kohler, 1999; Rizvi, 2018, Rogers, 2016).

As part of finding education for their children, parents attempt to obtain a diagnosis for their child. They are the first people to detect the differences in their child's development (Midence & O'Neill, 1999) and this feeling leads them to search actively for an explanation for their child's behavior. This might be relevant to their perception of the disability from medical model perspective that the problem is within their child. They generally recognize the symptoms and suspect the child's condition even before the official diagnosis is made. Parents feel that they want to know as soon as possible the explanation for their child's behaviour, though doctors sometimes feel unsure of the exact nature of the child's condition. However, sometimes, if the diagnosis is not correct or cannot be reached, parents might feel confused, despairing, and guilty (Midence & O'Neill, 1999). Many parents have to visit three or four different psychiatrists before getting an accurate diagnosis. There are parents who struggle with delays or difficulties in the diagnosis process (Kohler, 1999). Consequently, parents experience stress and an inability to cope with their child's condition. This also results in difficulties for the parents, such as being isolated by other relatives and friends. Mothers may also blame themselves for their child's ASD. Midence and O'Neill (1999) also explained that parents feel dissatisfaction with the diagnosis given when they first seek help and have doubts about the diagnosis given to them initially. However, when the diagnosis is complete and a label is given to the child's condition, parents tend to feel relieved and happy that they understand their child's behaviour, eventhough this diagnosis confirmed their worst fears. This is because someone else corroborated what they already suspected (Midence & O'Neill, 1999). ASD is invisible in nature and this may lead to misunderstanding by other people and cause difficulties for parents, who have to explain the nature of the child's behavioural problem themselves. This is unlike the case with other conditions such as Downs Syndrome or physical impairments. According to Midence and O'Neill (1999), parents feel that they are able to understand their child's behavior once they know what is 'wrong' with their child. Regardless of the difficulties they encounter with the child's ASD, parents usually have realistic expectations for their child's future, and they take an active role in the management of the condition.

Parents may encounter challenges in identifying and obtaining ASD-related support, because many children with ASD experience difficulty in expressing their strengths, weaknesses, and needs. However, Kohler (1999) found some evidence that suggests that professionals view families as unreliable sources of information. Parents face challenges in identifying and accessing the services that they need because either they or professionals fail to cooperate in planning, implementing, and evaluating services, or service providers are disorganized or lack continuity (Kohler, 1999).

Kohler (1999) argued that some parents have the initiative to keep everyone informed and insist that providers collaborate with them in planning, implementing, and evaluating services. On the other hand, there are other families who feel unsure that interagency collaboration is an important element of the service delivery system. The struggle that parents face is about who knows the child better the parents or the experts (Rogers, 2007). Parents think they know their child's condition better than experts, but they are asking for advice from the experts. It is generally held that there should be collaboration between families and agencies in order to ensure that children with ASD and their families receive the intervention that is required (Hadidi & Al Khateeb, 2015). Families are required to interact with different service providers to gain assistance for their children. It is the responsibility of service providers to develop service plans jointly with parents (Kohler, 1999). A major problem with this is that communication between parents and service providers can be ineffective, according to parents' reports (Rogers, 2007). Parents feel that professionals do not usually listen to them (Fong, Wilgosh & Sobsey, 1993). However, parents do respect professionals who have daily contact with them and appreciate their experiences in the field of ASD. Some problems are also associated with parents hoping that their children will be educated in mainstream settings, regardless of their disability, and end up not being able to get that. This is a struggle for parents with disabilities and is even more so for parents of children with ASD.

According to Hadidi and Al Khateeb (2015), when parents succeed in receiving the support, they are fighting for, they can then struggle with inadequate service delivery. Parents have reported that their major problem was learning about and accessing services, or that they were not given the choice to fight for what they wanted. In fact, in many cases, parents received something different from what they requested or found that there were not enough resources available for their children (Rogers, 2007). Parents can often perceive the delivery systems of service providers as problematic and believe the providers to have organizational issues or lack responsibility. Lack of communication or weak communication with parents might cause problems in the delivery of adequate services for children with ASD and their families (Hadidi & Al Khateeb). These challenges could create dissatisfaction in parents about service delivery for children with ASD.

To sum up, raising a child with ASD creates challenges for parents and especially mothers as they are considered the primary caregivers for children. Children with ASD exhibit symptoms of deficiency in social communication and repetitive patterns of behaviour, and they also exhibit a wide range of other behavioural ‘symptoms’ (APA, 2013). This seems to make parenting stressful and demanding. Parents of children with ASD report higher levels of stress than parents of typically growing children and parents of children with other disabilities. Parents’ experiences may include aspects such as emotional experiences, reaction to the diagnosis of ASD, social experience, parental and family relationships, social participation and social isolation, formal and informal support, perceptions of the child’s independence and future, and the mother’s experience with service provision for their children.

3.7 Parents’ perception of child’s independence and future

Many parents, especially mothers, experience concerns when caring for a child with ASD as they attempt to develop the life skills that would enable them to live an independent life in the future (DePape & Lindsay, 2015, Findler, et al., 2016). In DePape and Lindsay's study (2015), which involved a systematic review of 31 articles and the study of parents (involving 160 fathers and 425 mothers), it was found that parents reported concerns about their children's future. Many of them thought that their child would achieve typical milestones, such as being independent, living on their own, and finding secure meaningful employment. Parents reported a desire to make their child as independent as possible (DePape & Lindsay, 2015). The parents were interested in fostering and observing their child's ability to relate to and communicate with other people. They were interested in the child's progress and the speed at which they could learn new things. Mothers expressed a desire to see their child become independent in handling daily activities in order to enable him/her to attend school and achieve independent living and find work. Other studies found that parents may be worried about their child's future (Ilias et al., 2018). Parents reported that they were worried about maintaining their own health as their child was dependent on them for daily activities, and parents were concerned about who would care for them when they grew older. Some mothers also emphasized the importance of their children attending school and receiving formal education. They believed that if their child could become sufficiently educated, people in the community would no longer regard them as having ASD (Howlin et al., 2004). Better access to more extensive and appropriate supported living and employment schemes could enable much greater progress for children with ASD in the future (Howlin et al., 2004).

These feelings could be associated to parents understanding of disability as discussed in section (3.2). Even though, there is an understanding of the social barriers to their children's disability, there is also commitment to find treatment for it. Fisher and Goodley (2007) argue against linearity life models in mothers' understandings of disabled children's development. Linear life model links to the medical model whereby rehabilitation and cure is the key: "it is overwhelmingly, although not always, mothers who are the primary carers of children, and this is more the case when the children are disabled" (p. 67). Some parents are highly critical of the social value attributed it normalcy and distinguish of their child capability from how they feel about and value their child (Fisher & Goodley, 2007) and their independence.

3.8 Parents' experiences with services for children with ASD

Parents, and specifically mothers, have expressed a few reasons for satisfaction (Whitaker, 2007) or dissatisfaction (Starr & Foy 2012) with their children's education. For example, Whitkar, (2007) investigated 350 parents of children with ASD attending mainstream schools exploring their experiences, views, attitudes and level of satisfactions. 61% of parents reported themselves to be satisfied with their children's education. Their satisfaction was attributed to staff understanding of the children's difficulties, the school being flexible and continuous communication with parents. However, parents in Whitkar's study (2007) expressed many concerns regarding the schools roles' in promoting social development and social relationships.

However, in some studies, parents expressed difficulties in accessing medical, educational, and social services for their children with ASD, but there was satisfaction with the quality of services reported in other studies (Starr & Foy 2012; Whitkar, 2007; Band et al., 2010). A qualitative study conducted in Canada by (Starr & Foy 2012) explored the dissatisfaction of parents (N=143) caring for children with ASD with the services provided by healthcare professionals, educational services, and social services. In this study, parents responded to open-ended questions in a survey and expressed reasons for their dissatisfaction with their children's education as well as desires to ensure more effective education. The study noted that families experienced dissatisfaction and frustration with service delivery (Starr & Foy 2012). Another qualitative research study also reported that parents (N= 65) experienced a shortage in social services, including a lack of services that could provide care for their children with ASD (Band et al., 2010). The study identified a lack of confidence in such services and no mutual understanding between the professional and the parents, which affected the parents' trust in the professionals (Band et al., 2010).

Parents spend considerable time, energy, and financial resources on accessing services due to the poor coordination and often non-responsive systems of service providers (Bromley et al., 2004). Parents have expressed the view that they felt they needed to advocate for their children's rights in different settings such as educational, healthcare, and public settings. Bromley et al., (2004) in a qualitative study conducted in England found that mothers (N=68) devoted considerable time to accessing services, which added stressors to those that they were already dealing with (Bromley et al., 2004). The majority of mothers reported that their needs were unmet for practical support and respite care (Bromley et al., 2004). The society sets barriers against individuals with disability employing measures for accessing public spaces and the lack of financial support or segregation among others that exclude and isolate people with disabilities (Gabel, 2018).

Some parents reported that many service providers did not understand their children's needs and abilities. For instance, a study conducted by Parsons and Lewis (2010) found that parents' reasons for home educating their children with ASD was that they thought that schools could not provide a suitable programme, or that they had had negative experiences such as the bullying of their child at school, rather than it was being anything to do with an innate desire to home educate their children, as was mentioned in home-schooling.

Hodgetts et al. (2017) surveyed 143 parents of children with ASD in Canada and identified barriers to parents accessing medical care, family support services, information on services, and continuous support services. However, the parents viewed the funding and the professional support positively (Hodgetts et al., 2017). Caring and supportive people across all service areas have the capacity to positively affect the parents' experiences (Hodgetts et al., 2017).

3.9 Summary of chapter three

This literature review has covered different understandings of disability, the definition of ASD and the issues around it, such as its causes, prevalence, and diagnosis. The review has also covered the definition of education and issues surrounding the provision for children with ASD. Although the definition of ASD, causes, prevalence and diagnosis are not the main focus of the present study, exploring the definitions and concepts provides a good background for the topic. The main focus of the study is mothers' experiences with their children with ASD and the choices they make for their education.

The available literature largely focuses on parents of children with ASD rather than paying attention specifically to mothers. Although many of the participants in previous studies have been mothers, they were rarely the sole focus; this study intends to solely focus on mothers.

Many of the research studies were conducted through surveys or online questionnaires. Most of the studies in Oman were also conducted through the use of questionnaire (see table 2.2 in chapter 2). This chapter looked at the previous studies related to the topic of this study; the area of ASD as treated in this study is under-researched, especially in a country like Oman, as most research in ASD has been conducted from a medical perspective (see Chapter two section 2.6). Very little research on this topic has been conducted in Oman in the form of a qualitative study.

As shown in this literature review, little research has been conducted to investigate mothers' experiences with the choices and decisions they make for their children with ASD, whether in Oman or elsewhere. Some studies have focused on mothers' wellbeing and ability to cope coping when they have children with ASD, but there has not been much investigation into mothers' experiences when it comes to their children's education and what choices they make for them and why. In general, the literature that is available with regard to experiences is mostly about parents' perceptions of the services available in different settings.

Chapter 4: Methodology

4.1 Introduction

This chapter examines the methodology used for this study and the philosophical approach adopted and the research design will be presented in order to outline and justify the study. There will follow a description of the three research method phases, the participants, and the rationale for selecting them. A detailed description of the data collection methods and the process of piloting and conducting each phase will be provided. There will be a discussion of the process and procedures of data analysis and the ways of presenting the findings. The chapter will also discuss issues around research quality and ethical considerations of the research, and it will conclude with research methodology constraints.

4.2 The starting point

The general purpose of the current study is to investigate Omani mothers' lives with their children with ASD, and the decisions and choices they make about their education. The research articles reviewed in Chapter 2 about parents' experiences with their children with ASD, especially those published in the Omani context, seemed to 'measure' different aspects of parents' experiences: for example, Al-Farsi (2016) measured 220 parents (107 fathers and 113 mothers). Some articles used quantitative data by using questionnaires in order to find out percentages, to obtain a better understanding of parents' experiences (see Chapter 2). What was being investigated in many of the studies referenced in Chapter 2 appeared to be elements around ASD which were mostly on the medical side, such as screening (Al Maskari, 2018) and clinical assessment of certain behaviour in children with ASD (Al-Kindi et al., 2016). This knowledge is definitely useful and serves to understand different elements and aspects of ASD in Oman, as it is a new field. However, it does not seem to acknowledge the context of parents' experiences, which is important to explore. The methods of 'measuring' arguably fall short when it comes to understanding mothers' lives with a child with ASD and their understanding of the child's education. Consequently, these do not seem to be sufficient when it comes to understanding the mothers' lives, the way they experience their child's education on a daily basis, and what influences their choices and decisions. Despite the importance of medical research in Oman, research has not considered the need to explore parents' experiences with their children with ASD, and their choices and decisions for their education. This study is seeking to bridge this gap.

I started the introductory chapter with the story of my own experience with my son who is on the ASD spectrum, and so my research topic emerged from my interest as a mother of a child with ASD. In addition, I was inspired by McDonald's book (2014) and doctoral thesis (McDonald, 2010), set in Australia, about how mothers deal with the education of their children on the autism spectrum. There are a few common aspects between McDonald's thesis and my study, as well as differences. There are variations in the methodological approach used and the methods, such as conducting a series of case studies, and while her study followed the feminist and ethnographic research, my study is informed by the narrative approach. In addition, McDonald (2010) conducted her research on parents while I focused on mothers' experiences. In general, I started with McDonald, but my focus, my research approach and method of interpreting the data are different.

4.3 Formulating research questions

Research questions are considered to be at the centre of a study (Kumar, 1996). They identify what the researcher is setting out to uncover and are "the first and most important step of the research process. it is like the foundation of a building" (Kumar, 1996, p. 35). Formulating a research question is the centre point of the research process, because a well-articulated research question determines the route and helps to undertake the route to find an answer to the questions (Punch, 1998). As was noted in the literature review (Chapter 3), the gaps identified in the area of "Mothers' choices in educating their children on the autism spectrum" motivated me to gain further insight into Omani mothers' methods and strategies for choosing an education for their children with ASD. There has been a lack of understanding of mothers' experiences, which guided me to choose research questions aimed towards providing rich and in-depth descriptions. Therefore, my research questions assist in exploring the experiences of Omani mothers in their lives with their children with ASD about the educational decisions and choices.

The research questions are:

1. How do mothers experience their lives with their children with ASD?
2. What is the meaning of 'education' for mothers in relation to their children with ASD?
3. What are mothers' experiences, perceptions, and feelings about the educational services provided by the government for their children with ASD?
4. What influences mothers' choices and decisions regarding educating their children with ASD?
5. How do mothers experience the challenges or barriers, if any, in choosing an education for their children with ASD in Oman?

The above questions were formulated to allow enough flexibility and depth when gathering data (Mantzoukas, 2008), and thus the gathered data will help to answer these research questions. Robson and McCartan (2016) stated that research questions help understanding an unresearched area, with the purpose of unearthing new insights. The research questions aimed to seek new insights that could open new meaning and research opportunities in the field of ASD in Oman. In this context, the study is aiming to explore experiences, and thus the research questions above configure the purpose of the study, which is primarily to gain insight into how mothers choose the education of their children who have been diagnosed with ASD. Thus, through this study, I have striven to search out knowledge that can help me better understand what influences mothers' experiences and gain an understanding of the education of their children with ASD. Furthermore, my objective has been to gain a better understanding of how mothers choose an education for their children, with their experiences of their diagnosis, and the characteristics associated with the condition that could affect their choice of the children's education. My hope was that these research questions would help me to understand these issues through listening to the mother's stories about their children, from their birth and throughout their life.

4.4 Philosophical stance

The main goals of this study are to explore mothers' lives, choices, and decisions with regard to their children with ASD. The main goals of this study are to explore mothers' lives, choices, and decisions with regard to their children with ASD through listening to mothers' narratives about their experiences, perceptions, and feelings.

4.4.1 Qualitative research

Qualitative research reflects the interpretive research in which it considers "knowledge as socially constructed and concerns with meanings and the way people understand things" (Denscombe, 2007, p. 333). The need for the interpretive approach is that the knowledge is constructed through each individual's own interpretations and experienced (Denscombe 2014). As noted by Merriam (2015) that interpretive research perceives reality as socially constructed and accepts various interpretations of a single phenomenon. Therefore, the perceptions of each individual matters.

The interpretivist lens does not perceive meaning as fixed, but rather as socially constructed and changeable situation based on an individual's personal experiences and how he or she understands the world (Creswell, 2007). Interpretivist researchers often seek to understand their participants' experiences and perceptions regarding social, cultural practices and to acknowledge such experiences as valuable, unique and worth explorations (Merriam, 2015). This is how knowledge is constructed and known through the subjective experiences of people.

Furthermore, interpretive research develops the research's knowledge and encourages him or her to reflect on the data in the light of discussion with participants and their interpretations regarding the topic being investigated (Bryman, 2012). Considering these philosophical assumptions of the qualitative research, this study follows the interpretive framework in order to explore the Omani mothers' experiences about their children of ASD and how they choose their educational perception. I will adopt a narrative approach as a method which is under the interpretive approach.

4.4.2 Narrative approach

In much qualitative research, data collection is viewed as a negotiated interaction and a conversation between researcher and participants (Taylor, 2008) in order to reproduce stories about the participants' experiences. These stories (narratives) represent accounts of participants' lives.

A narrative approach is a specific qualitative method which focuses on the stories that people use in order to understand and describe aspects of their lives (Robson & McCartan, 2016); it can enable the construction of detailed stories and experiences of participants (Creswell, 2006). According to Robson & McCartan (2016), it differs from storytelling, as storytelling often means retelling by others, though the two terms are frequently used interchangeably. Narrative research has the interest of aiming to understand and carry the meaning for an individual of their own experiences (Robson & McCartan, 2016). My aim was to co-construct and understand individuals' realities and a narrative approach seemed appropriate to enable me to gain an insight of the meanings individuals ascribe to such realities. Research using a narrative approach, whilst usually framed by the experiences of individuals, is designed, however, to contribute to developing an understanding about "how and where the stories are produced, which sort of stories they are, and how we can put them to intelligent use in theorizing about social life" (Silverman, 2013, p. 111). In this study, individual participant mothers described their different experiences and explained their feelings and perceptions about being mothers and their choices and decisions for their children's education, through their written accounts, interviews and rapport-building days. Together, however, their experiences relate to broader social contexts around ASD, and events and experiences generated in Omani society.

According to Creswell and Poth (2018), there are four different types of narrative: biographical, autobiographical, life history, and oral history. This research incorporated two of these types: biographical, and oral history. Biographical narrative is studying the narratives of others, while oral history consists of gathering personal reflections of events, their causes, and the effects of one individual on several individuals (Creswell & Poth, 2018). In the current study, it explores the effects of having a child with ASD on others. The focus on these two types was based on their features that helped combine the participant mothers' stories of past and present experiences. The use of both biographical and oral history narratives was to assemble experiences of the participant mothers of children with ASD as a way to understand their lives with their children and the experiences and challenges they face in order to choose education for them. Narrative research was used to explore experiences of mothers, through interpreting their written or oral stories in a meaningful way (Riessman, 2008). It could help me to better understand the mothers' experiences and perceptions about their children with ASD and may come closer to representing the context and integrity of their lives more than the use of quantitative research. I thought that the narrative techniques would provide me with flexible agenda, rather they tend to let the participants to control the direction and the content of the research.

The study used a narrative approach to address the research questions (see section 1.5). The approach was applied through a dynamic interaction among research questions, experiences, conversation as well as reflection. The research started by collecting participants' stories about their lives, experiences, perceptions, and feelings about their children with ASD.

There are many features of a narrative approach which seem to link to how the participant's voice is ideally paramount; a narrative approach emphasises this. It facilitates the participants' communication in order to construct their own story, which helps them make sense of their lives. Through this research my intention was to give a voice to mothers of children with ASD. Riessman (2008) stated that a researcher needed to hear the voices of individuals by interpreting their stories. In this way, the researcher is giving participants' data more weight as they are not simply participating in the research by answering questions but have equal status to the researcher by constructing and reconstructing their life stories. I also wanted to allow participants' voices to be heard through different types of data collection methods. According to Riessman (2008), the use of narrative can facilitate the communication of mothers, enabling them to externalise their feelings and to indicate the elements of their experiences that are the most significant, in order to inform the researcher.

This approach can provide me with key experiential themes in the participants' conversations and may shed light on the meaning that these experiences hold for the participants (Creswell & Poth, 2018). Narrative enables sequence and deeper meaning (rather than ordered questions), as I used it to explore and understand the whole story through the process of listening/reading about the mothers' experiences. It also provides the opportunity to work with experiences as a whole story, rather than working on parts of participants' stories. Narrative structures organise and give meaning to experiences, but there are always feelings and experiences not fully encompassed by the dominant story (Bruner, 2004). Mothers could form their experiences into stories, and then their lives are influenced by their stories, suggesting that their stories with their children are created into a narrative: they have a beginning, a turn of events, and an ending. This can extend to a wider coverage of examples and feelings of the narrator. "Narrative, then, allows for (lived) experiences to be constructed in lived time and rendered eventful by being plotted into a story" (White & Epston, 1990, p. 127). In relation to my study, I wanted to encourage mothers to narrate their experiences and help them recall how the events occurred.

A narrative approach emphasises stories of personal and social lives (Mcleod 2011; Crossley 2010). Riessman (2008) suggests that such personal narratives can be used by narrators as ways to claim a sense of identity and to construct one's life. A narrative approach provided me with the opportunity as a social researcher to ask participants to reflect on their experiences through narrating their stories by themselves based on a number of prompts, which can be considered to be biographies. Then I wanted to explore and elaborate upon these biographies through in-depth interviews.

The narrative approach supports to explore major concepts of mothers' experiences that, due to the behavior of their children, mothers sometimes give up their lives and find it complicated to interact socially. The data from mothers showed that their various experiences of parenting children with ASD meant that they were subject to major stress. Being the mother of a child with ASD was considered as being at a higher risk for various family 'problems' as well as emotional complications (Wilson & Landa, 2019). This study depicts the experiences of a mother choosing services provided by the government, specifically educational services. Mothers of children with Autism (ASD) encounter multiple challenges in different stages of life. Most of the mothers encounter challenges in identifying the essentiality of services and the requirement for planning the service to meet their children's needs. The narrative approach helps to address mothers' experiences in the form of narrating, describing and examining events that happened to them since the birth of their child with ASD. Through the use of narrative, it is hoped to report how mothers strive to receive quality within the field of education and services as well as the process they follow in order to find such services. In addition, there is a need to understand the mothers' experiences of the quality and the availability of the services in different areas in Oman and to include all the related aspects. These cover staffing within schools and centres, funds, educational system in Oman in relation to children with ASD, and the level of awareness among different community organisations. Using a narrative approach and its specific methods in this research would enable mothers to tell stories, and engage with their emotions.

I was also drawn to a narrative approach and narrative methods because they enabled me to go back to participants by providing a second opportunity for them to reflect on their biographies and elaborate on the ideas written in their stories. The narrative approach provides an opportunity for the researcher to read and listen to the participants' biographies and build on them in an interview.

Narratives are useful and valid in identifying how the mothers experience their lives with their children with ASD and could enable me, the researcher, to carry out ethical research using relevant literature, "thorough data collection, methodological competence, coherence and transparency" (Yardley, 2008 p. 244).

A narrative approach features the process of sense making, through story telling (White & Epston 1990) more than other methodological approaches do. McLeod (2011, p.31) defines narrative as a "story-based account of happenings" which "contains within it other forms of communication in addition to stories". This is important to the study because it allowed the participants to tell me about their experiences as mothers and about what they believed was important, for example, about mothering their children with ASD and understanding their lives with them. In this way, the mothers were also, perhaps, making sense of their own lives. The process of sense making was for the participants and also for me as the researcher.

I chose a narrative approach to answer the research questions through a number of data collection methods. One reason for using different methods is because the narrator might not tell the whole story in one phase so different data collection methods could provide in-depth data from story narrations, from in-depth interviews and also from being part of the participants' days. Moreover, these different methods allow participants to tell their stories in different ways. The data collected from story narration and interviews was based on Wengraf's (2006) Biographical Narrative Interview Method. This is an approach to narrative interviewing used for both the individual and the collective. The biographical narrative interview is an example of one such in-depth interview. This relates to the importance of exploring e the real lives of participants within the present study. The use of a biographical narrative tool is important, given the centrality of stories to all of our lives (Kearney & Griffin, 2001). The Biographical Narrative Interview Method (Wengraf, 2006) assumes that conscious and unconscious concerns make up narrative expressions and these occur at cultural, societal and individual levels. This is particularly useful when studying the experiences of particular participants, such as parents of children with ASD. As a researcher, I might not have a direct influence on the mothers, but my goal was to explore, collect, and to analyse the detailed and nuanced experiences of mothers. According to Bruner (2004), the narrative approach requires information to be gathered over a considerable time period, and so I collected data in two different period of time, separated by five months.

A criticism leveled against narrative research, for example by Creswell and Poth (2018), is that it is a challenging approach to use, as the researcher needs intensive information about the participants and a clear understanding of the context, to make sense of people's experiences and communicate their meanings (Riessman & Speedy, 2007).

4.5 The research design

Research designs are procedures that start by identifying the issue, collecting data, interpreting and presenting data, and publishing results in research studies (Punch, 2014). They present ways of doing research studies and executing the associated procedures.

This study aimed to investigate Omani mothers of children with ASD: their experiences, perceptions, and feelings about their lives, along with their choices and decisions for their children's education. Therefore, I needed to ensure that the research design reflected the purpose of the study. Since the research questions were not looking for causal determination, prediction, and generalisation of findings, a qualitative approach was taken to answer them. This approach also, provided the opportunity for a more in-depth understanding of the research questions (Bryman, 2012). As it was mentioned in section (4.4.1) qualitative designs are suitable in order to explore the meanings individuals or groups ascribe to a phenomenon (Robson & McCartan, 2016). In addition, I intend to seek understanding of the mothers' lives and the way they experience ASD, and the way they experience choices and decisions. Qualitative research is important because it supplies the researcher with interpretive methods that are sensitive towards contextual factors and place the researcher in the midst of the study (Creswell, 2017). These methods can provide a degree of flexibility in their design. Robson & McCartan (2016) stated that the methods provide the researcher with rigorous data collection procedures and transparent analytic procedures, which may lead to valid and trustworthy findings. Figure 4.1 summarises procedures for conducting narrative research, as suggested by Creswell & Poth (2018). Figure (4.2) is about the three phases in my research design.

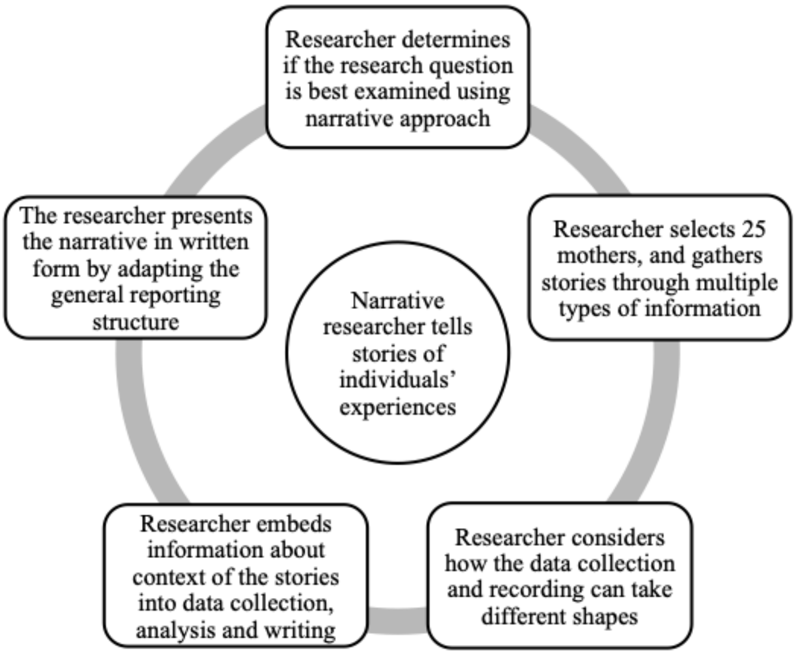


Figure 4.1: Procedures for conducting narrative research (Creswell, 2017)

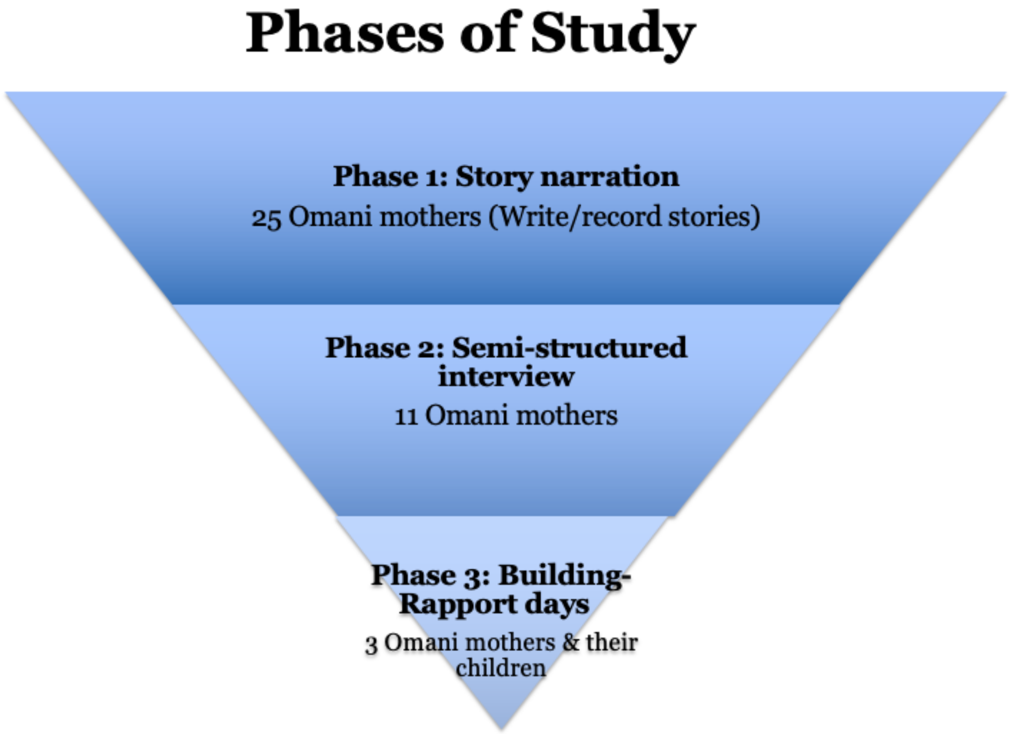


Figure 4.2: My research design for the recruitment process

4.6 Research participants and sampling

The participants in this study were mothers. The focus on mothers as opposed to fathers (either separately or as well) came from my experiences as the mother of a child with ASD, as detailed in Chapter 1, and because mothers are the main caregivers for children in general, especially in Oman. In addition, research (for example, Sifuentes & Bosa, 2010, cited in Gomes, et al., 2015) suggests that with parents of children with a disability, mothers are more likely to take a major caring role for their child. The focus on mothers is a reaction to her child’s condition after having explored previous research when reporting ‘parents’. However, a high percentage of those participants in a study by Cole, 2004, (cited in Ryan & Runswick-Cole, 2009) were usually mothers. The focus on mothers is not intended to minimise the importance of the other carers of children with ASD.

The sampling strategy for the three phases of the study, as illustrated in figure (4.2), entailed voluntary participation. Participants were involved in this research according to their willingness to participate and share their stories about their lives with their children with ASD.

Phase 1: Phase 1 involved story narration. This phase included 25 mothers who voluntarily agreed to participate. The recruitment of participants for Phase 1 was through a number of different routes (see section 4.7.1 below where I describe the data collection method in more detail).

1) The Oman Autism Society, an official organisation authorised by the Ministry of Social Development (MOSD) which deals with families of children with ASD, was asked to disseminate information about the research to families of children with ASD through WhatsApp (see information sheet form – Appendix nine). I sent an 'information letter' by email to mothers (see Appendix nine), with the help of the Oman Autism Society. This letter provided the participants with an overview of the research study.

2) Personal contacts, as I was part of a WhatsApp group (a chat application) consisting of Omani mothers of children with ASD. There were approximately 165 members in this group at the time of the study. (More details are summarised in Appendix one).

3) Snowballing (mothers who participated in the study invited other mothers to participate). Some mothers who were interested in the study introduced another likely respondent (Plummer, 2001; Goodson & Sikes, 2001). Mothers who participated provided other mothers with a summary of the study and gave them information on what would be expected of them. Again, any mother who contacted me was sent the information letter.

The choice of these three methods of recruitment originated from the need for an official organisation that might help me to access these participants, and I tried these one at a time. For example I tried the Omani Autism Society first, then, when I did not get enough response, I tried the personal contact. Then while I was collecting data a mother invited others to join to participate in my study.

Table 4.1 shows the recruitment strategies, the number of responses and the final number of collected stories in Phase 1.

	The recruitment strategy	The initial responses	The final number of collected stories
1	The Oman Autism Society contacted 97 mothers through WhatsApp application	5 responded with interest	3 stories were collected
2	Whatsapp group for mothers of children with ASD I contacted participants in three stages: 1. Contacted the first 20 members in alphabetical order, and waited for responses 2. Contacted the last 20 members in the WhatsApp group in alphabetical order 3. Contacted the next 20 members from the first alphabetical order in the WhatsApp group	29 responded with interest	20 stories were collected
3	Snowballing A mother invited two other mothers to share their stories		2 stories were collected

Table 4.1: The recruitment strategies

I contacted mothers through WhatsApp and sent them information and a consent form via email (see information sheet and form – Appendices nine in Arabic and ten in English). It was mothers' choice to record or to write their stories in Arabic or in English. In addition, it was their choice as to whether to send their stories to me via email, as an attached Word document, or as a photo, or as a photo via WhatsApp, whilst other participants preferred to audio-record their stories and sent these through WhatsApp. One mother felt that she had already created what I was asking her to re-construct, in a YouTube video and sent me the link to this.

The total number of mothers who shared their stories was 25 mothers of 28 children diagnosed with ASD. There were 24 boys and 4 girls from five different geographical locations in Oman: Al Batinah North, Al Batinah South, Muscat, Buraimi, and Salalah. The table in Appendix 11 summarises participants' backgrounds, to provide an overview of each participant. All their names are pseudonyms. Participants' locations are not included in the table for participants' privacy and to avoid possible identification. The highlighted participants are those who agreed to participate in phase two of the study. The mothers in this study ranged from 20 to 49 years old, and their children ranged between the ages of 4 and 17 (school age).

Phase 2: Participants in Phase 1 were asked, through the use of an information sheet (see Appendix nine) if they would volunteer to participate in an interview. There were 14 mothers who were interested in participating in Phase 2; however, three of them withdrew because of family circumstances. Therefore, 11 mothers participated in Phase 2, out of the 25 mothers who participated in the first phase.

Phase 3: Participants for this phase were volunteers from after the interview in Phase 2 when I had asked them if they would like to participate further. Phase 3, was to enable me to participate in an building-rapport day with the mother and her child. Three mothers agreed to participate in this phase

4.7 The study phases and data collection methods

This study followed three phases for data collection as shown in figures (4.2) and (4.3). The narrative approach was used in each phase. Phase 1 was a story narration phase, through the use of a form with some prompts (see Appendix nine), to provide the researcher with an overview about each mother and to give the background of her experience with her child with ASD. There were 25 mothers' stories. This was followed by a narrative-style interview phase; I had planned for a maximum of 15 interviews and was able to interview 11 mothers. The third phase was attending a day with a mother and her child to build rapport and be part of the mother's typical day with her child with ASD.

Figure 4.3: The study phases, data collection methods and participants (all names are pseudonyms).

The decision about the order of these phases was based on the research questions. It was important to have the broader narrative stories first to provide a background to the experiences, perceptions, and feelings of those mothers, before approaching them with narrative-style interviews. The interviews came as a second step, in order to elaborate upon, explore in greater depth, and fill in any gaps from the first phase. In exploring mothers' lives with their children with ASD, I felt that other research methods, such as interviews, text analysis, questionnaires or focus groups, though they might be useful, would limit the extent to which I, as a researcher could explore the multiple aspects of being a mother of a child with ASD. In an attempt to broaden these methodological methods, I decided to use building-rapport days to be more part of the mothers' lives with their children with ASD. My interest in using these days was a method in research to understand the mothers' daily experiences with their children.

4.7.1 Phase 1: Story narration

This phase started immediately after receiving ethical approval from the ethics committee team at the University of Exeter. A letter was sent to the head of the Omani Society team, asking for assistance in distributing the story narration guide. I waited for the participants from the Oman Autism Society to contact me, and a few agreed to participate (only four; see Appendix one for a summary of on the way of accessing participants). Then I sent WhatsApp messages to the mothers of children with ASD, to invite their participation. I sent messages about the three phases and waited to see how many would show interest (a summary of the whole process can be found in Appendix one). In general, 34 showed interest, and the consent form and the story guide were sent to them. I could only get 25 stories from participants. I received three more stories beyond the time I had specified for them. The whole process took one month: January to February 2018.

The use of story narration was generated from the idea of obtaining an overview of mothers' experiences regarding their lives with their children with ASD. The story narration phase focused on the collection of written or audio-recorded stories. Giving participants choice was chosen for a number of reasons. Firstly, because I was in Exeter and the participants were based in Oman, it was difficult to meet mothers and request their stories. Secondly, writing things down gives people more time to construct their thoughts. It was like an open-ended question for the mothers, with a statement and prompts to guide them through the construction of their stories. This was provided as the researcher would not be present to explain or clarify. The opening statement and the way that the prompts were worded directed the understanding of the participants, to help them (or ‘to enable them to’) construct their stories.

The story narration guide was designed to support the investigation of the experiences of mothers of children with ASD, and the statement and the prompts were designed with reference to mothers’ lives with their children with ASD, (as discussed in Chapter 2), with the help of my personal experience with my own child. The story narration guide included questions for demographic data about the name (not compulsory); mother’s age; child’s age; household income; child’s level of ASD; type of education the child attends/receives; mother’s highest level of education; and place where they live (see Appendix two- & three-story guide). The aim of including demographic data was to guide the choice of mothers in Phase 2, and these data might have had a relation to the findings, though in the end I did not need it. The guide also included a statement with some prompts, to guide mothers in constructing their stories. These prompts included the following: the diagnosis of their child and at what age they were diagnosed; the methods the mother uses to teach their child; the child’s progress (for example, academic, social, communication, life skills); the mother’s feelings since the diagnosis of their child; the mother’ decisions regarding their child’s education; the ways their family and friends relate to their child with ASD; the mother’s experience of teaching their child with ASD; and the mother’s experience of accessing education and using services for their child with ASD. I got these prompts from the research questions (see section 1.5).

I had in mind that mothers might be overloaded with work, taking care of their families and other personal matters if I presented a longer story narration guide. I gave them the choice of writing or recording their stories, as well as making sure that the prompts were clear and understandable. I took into account that the story guide started with an introductory section, including information about the study and instructions for completing the story narration guide.

A story narration guide was sent to participants, including the prompts as a rough guide to write or audio-record their own story (see Appendices nine, Arabic version, and ten, English version). The piloting experience, I believe, enabled me to modify and enhance the research questions, and made them suitable for collecting data. However, I did not change or modify the research questions, or the story narration prompts and I proceeded with the story narration guide.

It was important to pilot the story narration instrument, in order to ensure that the guiding statement and the prompts were clear and understandable by the participants. It was necessary to pilot the story narration guide before actually administering the questions, to provide evidence for participants understanding the prompts (Bryman, 2012). The aim of piloting the story narration guide was to develop and improve the questions, and to identify gaps and areas that needed to be addressed (Bryman, 2012). This piloting was important in order to refine the guide and become aware of problems that might be embedded in the design, and thus overcome them. These problems might be related to the clarity or ambiguity of the questions and the upcoming issues, and it might be important to include these in the guide. Therefore, the story guide was piloted with two mothers who were not part of my research sample. They were recruited from the WhatsApp contact and they voluntarily participated. The piloting experience aimed to enhance the original themes and prompts and make the story guide suitable for collecting the desired data.

The story narration guide was piloted in January 2018 and a set of questions were sent to the piloting participants. These were the questions:

- How long did it take you to complete the whole task?
- Were instructions for completing the task clearly written?
- Were questions about the demographic information easily understood?
- Were prompts for constructing your story clear?

- Did you understand how to construct your story using the prompts?
- Did the prompts help or constrain you in constructing your story?
- Are there any other prompts that would have been useful?
- Was the task to be completed exhaustive?
- Did you understand what to do with the completed task (sending it via email/WhatsApp/or handing the hard copy to the researcher)?
- Did you understand when to return the completed task?
- In the case of recording, did you know how to record?
- Do you have any suggestions regarding addition or deletion of questions/ prompts?
- Do you have any other suggestions that would clarify or improve the instructions?
- Do you have any other suggestions that would clarify or improve the whole task?

In general, piloting the story narration guide helped me identify the areas in order to improve it. Usefully, one of the participants recorded her story, and the other one wrote hers. The construction and the length of the story varied between the two. According to pilot participants, the story narration form had allowed participants to construct their stories in a sufficient way. The two participants stated that the prompts and the introductory statement supported their construction of the story. Reflection on the pilot story narration guide emphasised the clarity of demographic questions, as well as prompts for constructing the story. The participants in the pilot reported that the prompts allowed them to focus on certain points in order to narrate their story, rather than narrating randomly. They also added that the instructions were clearly written and easily followed. The form provided a space for the participants to express their experiences, perceptions, and feelings about their story, as they said.

The decision was made to use email in order to send the story narration guide to my participants, as suggested by the pilot participants. It was mothers' choice as to whether to audio-record or to write their stories; it was also their choice whether to do so in Arabic or in English. These choices were made to make it more convenient for the participants and to encourage them to participate in the study. In addition, it was their choice whether to send their stories to me via email as an attached Word document, or as a photo, or as a photo via WhatsApp. One mother felt that what I was asking her to (re)construct, she had already created in a YouTube video and sent me the link to the YouTube video.

Table 4.2 presents a summary of the types of data collected in Phase 1.

Written stories in English	Written stories in Arabic	Audio-recorded stories	YouTube video	Total number
2	18	4	1	25

Table 4.2: Number and types of participants in story narration phase

The story narration phase helped me in gathering many ideas related to mothers' lives with their children with ASD and the decisions they made for their children's education. However, mothers constructed their stories differently and there was a need for more exploration of different aspects, such as their experiences about the available services in Oman. In addition, this instrument was convenient in aiding me to reach mothers and to create an overview about them before approaching them for an interview in the next phase. They were asked in the information sheet about whether they would volunteer for the interview and 14 accepted the invitation. In general, after I had sought an in-depth overview about the mothers' experiences, I was able to construct the interview guide in order to undertake the interviews with my participants.

4.7.2 Phase 2: Semi-structured narrative-style interviews

Interviews provide a voice for participants and help the researcher to explore their experiences (Seidman, 2013). In this study, the narrative- style interviews (hereafter “interviews”) permitted the researcher to investigate the complex issues surrounding the choices and decisions mothers made around education for their children with ASD, and their experiences throughout. According to Seidman (2013, p. 7), “I interview because I am interested in other people’s stories. Most simply put, stories are a way of knowing.” Thus, “telling stories is essentially a meaning-making process” (Seidman, 2013, p. 7), because participants recount an experience and reflect on its elements and process in order to make it meaningful to the listener. Interviews also allow for an in-depth way of examining the experiences of the participants and what they make of the experiences. Participants are telling their own stories to “reveal more about their own inner lives than any other approach could” (Atkinson & Flint, 2001, p. 24). Thus, the research method of interviews would allow participants in my study to elaborate on their thoughts about the topic from Phase 1.

The importance of in-depth interviews is to “identify individual perceptions, beliefs, feelings and experiences” (Hennink et al., 2011, p. 53). In addition, interviews assist in gaining the researcher to “gain in-depth information, identify personal experiences,” and establish “life histories as well as feelings”. Interviews are considered as useful methods for sensitive issues, in order to identify the context for participants (Hennink et al., 2011, p. 53). Thinking about different forms of interviews, I eventually decided to use semi-structured interviews rather than structured interviews in order to explore and understand the participants’ feelings and emotions, to match my research purpose. The questions were open-ended and were used flexibly, with prompts where necessary to facilitate participants’ in sharing their experiences. I was concerned that a lack of experience in probing the interviewees’ meaning behind their words could have impacted the result of my research (Seidman, 2013). As Seidman (2013) suggests, in-depth interviews need “skills to establish rapport, use motivational probes, listen and react to interviewees”. It was very important for me to show a genuine interest in the interviewee and the value of their experiences, and not to treat them as just a source of data. Fisher & Goodley (2007) also advise that interviewing may present some ethical considerations, especially for mothers of children with special needs, because it may cause them to recall experiences; in many cases, these experiences may be painful and blurred between diagnosis and therapy sessions, attempting to understand the condition, and thinking about their future.

The interview design

The interview guide was designed after reviewing the 25 story narrations constructed by mothers as I was seeking clarification about some issues that were raised by participants. The first phase gave participants the freedom to talk/write about their experiences, perceptions, and feelings about their lives with their child with ASD. Some of the stories in the first phase fell short in covering all the prompts, and many mothers focused on specific aspects, either the issues from diagnosis or their lives with their child in general, or only about the places where they attempted to enrol their child. Thus, the semi-structured interviews aimed to find out more about these experiences. Although the interview guide was never a final product and needed constant changes and development after each interview, and varied from one mother to another, I nevertheless found it useful to ensure that the same general and key themes and questions were included. In addition, I have taken Robson and McCartan (2016) into consideration when designing it: the introductory comments about the topic of the interview; the key questions; and closing comments. I developed my interview guide from McDonald (2010) with introductory comments, followed by a number of sub-questions for more clarification or simplification of the main questions (see Appendix two). The questions sought out mothers' experiences with their children – for example, their lives with a child with ASD; the meaning of education for them; the process of choosing an education for their child; the choices and decisions that were made to support their child's development; and their hopes and concerns about their child's future.

My presence in the in-depth interviews enabled me to clarify some queries from participants' story narrations and helped the respondents to expand and elaborate on their answers. According to Cohen et al., (2018) using probes enables interviewees to explain more fully and encourages them to participate in the topic given to them. Regardless of the fact that interviews are time-consuming and costly, they can be conducted in a controlled environment that reduces distractions and provides privacy (Cohen et al., 2018).

Participants in Phase 1 were asked if they were interested in participating in interviews. As shown in Appendix 11, 14 out of the 25 Phase 1 mothers agreed to participate, but three withdrew before interviews started for reasons of personal circumstance (there are no details of their withdrawal that are relevant to my study). There was direct contact with the remaining 11 participants through WhatsApp. We agreed on a convenient time and venue for interviews. I gave them the option to conduct the interview in a setting of their choice if they wished. Six of them chose their house for the interview, four asked me to go to their work places and one participant wished the interview to be carried out in a restaurant.

After having a general understanding of the 25 story narrations and identifying some common themes (see data analysis section 4.9), an interview guide was created. This guide drew upon McDonald's guide (2010) (see Appendix two) and was reviewed by my two supervisors. Finally, it was translated and reviewed by the mother of a child with ASD, independent from the study. The interview questions did not constrain me but were used to roughly guide the interview. There were many questions in the interview guide, but they were not used with each individual mother. Different questions were used for different mothers, as detailed below. Therefore, it was difficult to pilot the guide as the questions varied from one participant to another.

Before interviewing each mother, I spent an amount of time reading and re-reading their story narrations from Phase 1. I chose the relevant questions from the interview guide suitable for each mother and excluded the questions that were not relevant to that mother's story. During the interview, I posed questions to start the interview, and the mothers were invited to talk about their experiences of choosing an education for their child with ASD. Space was given to each mother to talk without me interrupting them, but there were times when I posed further questions to invite greater explanation or exploration around the events they mentioned. I continued in this fashion to also ask other questions from the interview guide. The interview was concluded by inviting mothers to reflect on any experiences that had not been previously mentioned and to talk about their feelings about their lives with their child with ASD and the services provided in Oman.

Audio recording of interviews was important for many reasons. Firstly, It allowed me to concentrate on what the mothers were saying, because eye contact and interaction were significant in these settings. The topic I was discussing with mothers was sensitive and required my full attention. Mothers were sometimes sharing some sensitive details about their children with ASD. This needed my interaction, so that mothers felt encouraged to share their stories. Some mothers did not initially feel comfortable with their interview being recorded, but I assured them that I would be the only one who would be listening to it. Then, all mothers agreed to the recording. The interviews lasted between 24 minutes and just over 2 hours (see Table 4.3).

Aseel 28 minutes	Athari 51 minutes	Fadwa 42 minutes
Fatin 1 hour, 25 minutes	Narjes 2 hours, 2 minutes	Shahad 1 hour, 14 minutes
Somood 24 minutes	Sondos 46 minutes	Shojoon 55 minutes
Thana 1 hour, 11 minutes	Zeina 1 hour, 41 minutes	Average time length: 1 hour, 4 minutes

Table: 4.3 Length of interviews

From Phase 1, there was a question at the end of the story guide to invite participants to take part in Phase 2. 14 mothers agreed to do so, but because there was a gap of three months between the two phases, three mothers withdrew for personal reasons. I conducted individual interviews with 11 mothers. For five of them, a convenient location and timing was arranged with each, and for the other six, the interview took place at their houses, at their arranged timing (see Table 4.4).

Convenient place	Their house
Aseel, Athari, Fadwa, Shojoon, Sondos	Fatin, Narjes, Shahad, Somood, Thana, Zeina

Table 4.4: Names of the participants in the places of the interview

The interviews were conducted in April 2018. All interviews lasted approximately 1 hour, and all were conducted in the Arabic language because it was the participants' mother tongue. I asked all the participants if they would prefer to conduct the interviews in Arabic, and they agreed on this.

During the interviews, many mothers were quite emotional when they were sharing their stories. It was difficult to remain neutral during the interview, as I struggled not to show emotion. For example, when interviewing Somood, I had to stop asking questions and get her to tell me her story without asking certain questions. The stories were emotional and personal, though in many occasions the mothers were sharing information not relevant to my study. For example, one mother burst into tears when she was telling me how she was forced to marry a man she did not want. It was difficult for me listen to them without feeling stressed and guilty, because in asking them to participate in the interview, I had caused that emotional response. Therefore, if any emotional distress occurred, I offered to stop the interviews; all participants insisted on continuing to talk. According to them, it was their chance to make their voice heard by someone.

4.7.3 Phase 3: Building-Rapport days

Building-rapport days has a central role in the research method as it provides a descriptive basis in relation to participants' beliefs (Punch, 2014). The features of building-rapport as a research tool give the researcher an opportunity to gather 'live data' in social situations (Punch, 2014). In this way, I could observe directly what was taking place instead of relying on reported accounts such as interviews, because what people do might be different from what they say they do (Robson & McCartan, 2016). According to Clough and Nutbrown (2002), building-rapport (observation) is more 'radical looking' as a method which looks for meaning as well as evidence. Thomas (2009) states that building-rapport day is “one of the most important ways of collecting data” (p. 183). It helps a researcher to gather in-depth information that supports other methods – in this case, complementing story narration and narrative-style interviews. I thought that this method would support my study in enabling me to understand how mothers’ experience their lives with their children with ASD as well as the ways in which mothers support their development. It was hoped that the building-rapport days would provide a rich understanding of the mothers’ experiences and feelings.

It was decided to carry out building-rapport days because this would give more time to be part of the mothers’ days with their children with ASD, such as their mealtimes, their preparation for school, and other daily activities. It was important for me to understand that each mother’s day would be unique and would provide individuality in participants’ experiences. I thought that the days would provide me with an insight into mothers’ lives, and, though there might be differences in their stories, it might support the findings from the interviews in terms of mothers’ understanding of the meaning of education for their children and their lives with their children. The process of observing a typical day with a mother and her child was not common in previous research. The structure of the building-rapport day was not planned but was unstructured in order to observe situations and actions as naturally occurring, and I decided to attend a day and observe the events experienced by the mother and her child in their natural setting (home). Building-rapport ‘days’ were arranged with three mothers, who volunteered from 11 interviews. In the end, the three building-rapport days were of very varying lengths. Detail around the content and structure of these days is included in Chapter 5, section (5.3).

My building-rapport method came from my existing relationships with mothers and my experience as the mother of a child with ASD. It would help me find out the strategies mothers use to deal with their children in different aspects, such as life skills, academic skills, or even social skills. I understood that I needed to be careful not to misinterpret mothers’ behaviour if the day went against my expectations, considering that I could be the cause of the behaviour, especially for children with ASD. However, there might be a better chance for a follow-up conversation, which might provide an opportunity to answer the questions about the challenges mothers face.

Three participants volunteered to participate in building-rapport days. This low number was understandable because in a place like Oman, where most families abide by cultural rules, it would be difficult to gather data from a same-sized sample as in the interview and stories. It would be difficult to use building-rapport days because of having to accept strangers to spend full days at the house, knowing that this might disturb the whole family. Thus, reducing the number helped me to get some people with special circumstances to accept me in their house, such as one mother whose husband was away for work, so it was easy for her to invite me into her house. The second mother was a widow and lived in the UK, so she could invite me to her house. The third mother's husband had a busy day, so I could join her in her house for few hours. Since my interest is to gather in-depth information and explore mothers' experiences, using three phases of a data collection method would be useful to identify the answers to the research questions.

The building-rapport days I carried out were focused on my being part of the mothers' lives with their child with ASD. They focused on what knowledge and strategies mothers had when dealing with these children. I did not design any guide, as I felt that it would not provide me with what I was looking for. However, I did plan these building-rapport days beforehand as I went through the mothers' stories and listened to the interview recordings. As one of the questions in the interview guide was about a typical day for a mother and her child with ASD, I had this question in mind and wanted to experience this day with them.

I understand that having a clear focus when carrying out a building-rapport days would make it better for a researcher to know what to look for or observe, so the researcher would know what to record out of the many things happening during them. However, it was important for me to see the variety of events in the day of the mother and her child.

However, I was concerned about the outcomes of the building-rapport days, in terms of data collected, and whether those fulfilled the purpose I planned for them. This will be discussed in the limitation section (see Chapter 7, section 7.5).

Building-rapport days are often criticised on a number of fronts: as being time-consuming; the researcher may be seen as ‘intrusive’; private information might be observed but cannot be reported; the researcher might not have good building-rapport (observation) skills; and children might present special problems in gaining a rapport (Creswell, 2017). Being part of these mothers’ days did affect the typical days for them as a family, which will be discussed in the limitations of the study (see Chapter 7).

In terms of conducting building-rapport days, I agreed with the participants on a convenient time for me to come to their house. These days were conducted in April and May 2018, after interviewing participants. As already mentioned, out of the 11 mothers in the interview phase, only three mothers agreed for me to join them for a day (see Table 4.5).

Name of the mother	Children with ASD	Other children	Length of stay
Fatin (in Oman)	Hassan (4 years old) Khuzam (was studying in another country)	Mihad (8 years old)	3 hours (to observe the session she was conducting for her son and other children with ASD)
Shojoon (in Oman	Hoor (9 years old) Noor (5 years old)	Khalil (4 years old)	24 hours
Zeina (in UK)	Obaid (9 years old)	Areej (10 years old)	36 hours

Table 4.5: Building-rapport days’ participants

On these days (for example, the 24-hour one), I did not observe for the full time as there were times for the children's sleep and time for their school day. The first building-rapport day with Fatin took three hours. The actual day took eight hours on the second day with Shojoon and her two daughters, while the building-rapport day with Zeina comprised twelve observed hours. Therefore, in total, I observed for approximately 23 hours. The three mothers varied in their motivation to participate on these days. For Fatin, she seemed to be motivated by the work she was doing with her son, as she explained the activities to me. For Shojoon, she seemed to want to talk to someone about her children, as she spent most of the time talking to me about different issues related to her life. For Zeina, she was more of a friend who wanted to help in my study. More details about the building-rapport days can be found in Chapter 5 (see Section 5.4).

I have chosen the methods previously cited, because firstly, mothers of children with ASD may be sensitive and may also have experienced trauma associated with their children's condition (Mercer, 2007). They might withdraw from the discussion because there are different levels of success for each child, and what seems a big achievement for one child might not be for another.

Some considerations needed to be taken into account during the conducting of the research. One of these was that the mother's personality and characteristics might impact on the gathering of data in all three phases. Some mothers may be independent in taking decisions to overcome challenges with their children, while others may not. Some mothers might be able to express themselves easily, while others might not. The researcher needed to consider this in order to react appropriately with each individual, by, for example, rephrasing interview questions in order to motivate them to talk.

4.8 Data analysis

In this study, qualitative data was collected in each of the three phases. For each phase, steps were made in order to organise, analyse, and present the data. There are four steps in analysing data which involve preparing and organising the data for analysis, exploring the data, and then organising it into themes through certain coding processes, and presenting some of it in figures or tables. These steps will be discussed in detail below under each phase.

4.8.1 Phase 1: Story narration data

Data preparation

The data preparation for Phase 1 started by transcribing (where necessary) and translating the story narrations. As shown in Table 4.2, 18 out of the 25 story narrations were written in Arabic, two were written in English, four were audio-recorded in Arabic, and one was a Youtube video in Arabic. The four audio-recorded stories and one YouTube video were first transcribed verbatim in Arabic, so that all story narrations were then in written form. The 23 Arabic stories were then all translated by myself into English. Translation is inevitably a sort of stage of interpretation. I tried to focus on the participants' words and to report their accounts in a readable way in this translation stage (Kvale, 2009) (see Appendix 3 for an example of a story narration transcript).

Initial analysis

Once the stories were transcribed and translated, I immersed myself in the data and spent time reading and re-reading the stories, which allowed me to become conversant with the mothers' stories, in order to develop an understanding of the data. I reviewed and read all the data thoroughly. I recorded initial thoughts through writing comments in the margins of the transcripts (see Appendix 4 for an example of this initial manual analysis for Athari). These comments worked as an important step to later form broader groups of data, which would be formed into codes, and later into themes.

Coding, categorising and identification of themes

The process of coding started by dividing the text into smaller units such as phrases, sentences, or – in some cases – paragraphs, assigning a label to each unit and then grouping them into themes (see Appendix 5 for an example of the coding process). Once I had codes from the first story narration I used these for the second and so on. If new codes emerged, I went back to the previous story narration in order to check I had not missed it out. A variety of themes emerged from each story describing the mother's life with her child. Examples included the following: The diagnosis of their child and at what age they were diagnosed; the methods used to teach the child; the child's progress (for example, academic, social, communication, life skills); mothers' feelings since the diagnosis; decisions regarding their child's education; ways in which family and friends relate to the child; experiences of teaching their child; experiences of accessing and using services for the education of their child. There were also as the support they had received during their journey with their child; the different types of support, either from family and friends; and how people around them reacted to their child's condition.

Presentation of data

A summary of each story narration was constructed to provide an overall picture of each participant. The summary included demographic information about the mother and her child, and some basic information from the demographic data such as the mother's and child's name, age, age of diagnosis, school/centre and ways of teaching her child in their own words. The themes fed into summaries through using the prompts from the story narration guide (fourteen summaries out of the 25 were included in the findings chapter (see section 5.2). The choice of these fourteen summaries was because Phase 2 will present the interviews of the other eleven mothers and it was to avoid repetition of the mother's stories. However, the stories of the eleven mothers can be found in Appendix 6.

4.8.2 Phase 2: Interview data

Data preparation

Phase 2 included eleven interviews conducted in Arabic and audio recorded. Initially, I listened to the audio recordings, in order to familiarise myself with the data, before transcribing them into Arabic. Then I listened to the recordings again and transcribed them into Arabic. Kvale (2009) noted there is no standard way to transcribe an audio recording and that it depends on the intended use of the transcripts; in this research my intention was to transfer the mothers' interviews in a readable way. I amended things to make them readable, (for example, leaving out hesitations, like ums and errs). Some call this cleansing the data. I then listened to the interviews again whilst following the transcription to ensure accuracy.

Initial analysis

I started to work through the transcripts manually. I tried to read the interview transcripts and write coding on the margins manually (see Appendix 4 for an example of manual coding). Following this, I grouped common codes into categories by creating bullet points that could be grouped together. These codes then transformed into themes in a word document, using one tables for each mother (see Appendix 5). Finally, I used a thinking map for each mother to enable me to understand connections and relationships (see Appendix 7 for an example). As an example of this, I wanted to categorize mothers' feelings for their children's diagnosis, so I grouped what they had stated about their feelings in a thinking map. I did this because I had noticed that each mother stated varied feeling (as an example). However, I did not do this for all the themes, because some themes encouraged me to use the maps. (An example in the Appendix 7 shows what I did and what I mean by a thinking map).

Coding, categorising and identification of themes

In the process of writing the analysis I went through all the interview transcripts to understand, draw connections, and identify the common themes and in many cases I was counting the number of mothers who shared similar ideas, codes and so on (see Appendix 7 as an example). Once I had identified the themes from all the interviews after coding and categorising, themes assigned to groups that addressed them. Coding and categorising of the interview data led to the identification of six key themes. These were: (1) purpose of education; (2) finding an educational placement, (3) strategies to support her child's development, (4) perceptions about the services available for children with ASD, (5) family/community support, (6) hopes and concerns.

Presentation of data

The process then helped me to think of the way of presenting my findings by writing about each mother and her child with subheadings that included main themes (see findings chapter 5). I reconstructed a story about each mother to provide an overall picture of her, but these stories have subheadings (as mentioned previously) to help the reader understand the meaning of each story in relation to the current research.

4.8.3 Phase 3: Building-rapport Days

In terms of the data gathered during the building-rapport day in Phase 3, the aim was to spend a full day with the mother and her child. As it was difficult to write field notes, audio field notes, using my phone, were recorded instead.

Data preparation

The building-rapport day recordings, in Arabic, were transcribed directly into an English written version, as they were my own notes in a readable way and in full sentences (see Appendix 11 for an example of building-rapport day). The reason for not transcribing these into Arabic and then English, was that I was able to recall the events of these days from the recorded notes and could translate them directly, unlike the story narrations and interviews. I could not work out the meaning of participants' conversation until I had transcribed it first.

Initial analysis

As I did in the first two phases, I went through the translated interviews manually and wrote my own notes in the margin. These notes were then grouped, coded and categorized as will be explained next.

Coding, categorising and identification of themes

The building-rapport day was coded using specific categories guided by the analysis of the first two phases and the research questions. The code was applied to the data. These categories were then compared to the themes from the first two phases (story narration phase and interviews phase). The Phase 3 data led to the identification of three themes (see section 5.4): (1) Omani mothers' lives with children with ASD; (2) family support; and (3) the mothers' strategies to support their children with ASD.

Presentation of data

Once the themes were identified, I reconstructed a summary of each mother's day. I also presented a table to provide more details about who was involved in these days (see section 5.4).

4.8.4 Cross phase data analysis

There was also a cross data analysis that included examples of data from different phases and different mothers (see section 5.5). I followed similar steps in the first three phases. I tried to look at the interrelated themes in order to find meaning of mothers' experiences from the three phases of data collection.

Data preparation

I identified common themes from the three phases (including mothers' quotes) and put them in one word document. I printed out each word document to work out meanings and connections.

Initial analysis

Initial analysis was done in the first three phases.

Coding, categorising and identification of themes

This step was done for each phase based on the previous phases. For example, Phase 2 was the basis from which to develop the themes for the cross analysis section in Phase three. I had to go back to the codes and categories from the other two phases to add and find examples from (interviews and building-rapport days) in order to back up the themes with examples from participants from the three phases.

Presentation of data

The data are presented in relation to each of these themes in the findings chapter. These findings are supported by figures and tables to help to clarify their meaning.

4.9 Research quality

It is essential to secure data quality in qualitative studies like this one. Thus, there is a need to assess the credibility and accuracy of the qualitative data and the findings, as well as the reflexivity of the researcher. Therefore, a discussion of these concepts in relation to the present study's design and procedure is of vital importance and is presented in the subsequent sections.

4.9.1 Credibility and trustworthiness of data

According to Graneheim and Lundman (2004), the credibility of research is related to the "focus of the research and refers to confidence in how well the data and the processes of analysis address the intended focus" (p.109), which suggests that credibility is considered to be seen from the outset of the research process, the focus of the research, the research site, the participants and the methods of data collection and analysis.

During the process of data collection and analysis, it is essential to validate the findings of the data (Creswell, 2013). Creswell (2013) uses the terms 'accuracy' and 'credibility' to describe the same things. I used three strategies to ensure credibility and trustworthiness of the data and the findings in my study: triangulation, member checking, and rich data descriptions. The first one is the process of corroborating evidence from participants (mothers) and the methods of data collection (story narration, interviews, and building-rapport days) in descriptions and themes (Punch, 2014). By doing this, my aim was to enhance the accuracy of my study.

In addition, in order to ensure accuracy of the transcription of the recorded interviews of the participants, I applied member checking, in which I asked two participants to check the accuracy of these transcriptions. I could not ask all participants to check because it was time consuming and not all of them agreed to do this. Therefore, two participants voluntarily agreed to read the transcripts, so I sent each the actual transcript of the interviews, requesting them to verify their accuracy. I also passed them the Arabic transcript along with the English translation to check the quality of my translation. The two of them confirmed the accuracy of the transcripts and translations.

Furthermore, I have provided a rich data description of the data, such as the setting and description of the participants. This is presented in the findings chapter to address each theme with descriptive data from the participants. The purpose of using different data collection methods was to triangulate the study findings. Triangulating data is common in research to help to increase the validity of research findings (Robson & McCartan, 2016), though triangulation needs to be conducted carefully as the findings collected by different methods might contradict each other in a problematic way (Robson & McCartan, 2016). However, I did not find it problematic, as the three phases added information to each other and supported the in-depth understanding of mothers' experiences.

To conclude, in the analysis stage and after writing (and translating) the stories for each participant, I reconstructed a comprehensive story that preserve participant's voice (Coulter & Smith, 2009). In the findings chapter I use short direct quotes about participant's experiences and tried to retain some elements such as specific events, timing, personal information about the mother and her child. My overall goal in this process is to preserve as much as possible the participants story without my interpretation and at the same time to become familiar with each participant's narrative.

Once all the narratives analysis leading to summaries, I engaged in a second level of analysis. It is, at this point, my own interpretation of participants accounts. I wanted to seek similarities and differences in patterns across participants accounts and across the three phases of data collection methods in order to reach to more in-depth understanding of their experience. At the second level of analysis in qualitative analysis, I employ emerging coding schemes and included constant comparison with attendant procedures to establish trustworthiness (Mile & Huberman, 1994).

4.9.2 Reflexivity

As the mother of a child with ASD, I played a role in this study of reflexive insider. Woods et al. (2016, p. 387) explained that the reflexive researcher is “the researcher’s self-awareness and understanding of what they bring to the research act: their capabilities, knowledge, experiences, values, hopes, fears as well as their epistemological assumptions.” Thus, it was important for me to be a self-reflexive researcher, in a way that helped me to explore similarities between me (as a mother) and my participants, and to use my own experience to understand and interpret the data. However, this can be challenging as well, because carrying out reflexive analysis can always be problematic and might make it difficult to explore the experiences as they are invariably complex, ambiguous, and ambivalent (Woods et al., 2016). Being preoccupied with my own emotions and experiences could have skewed my research findings in an undesirable way and could have blocked my participants’ voices. In consequence, I attempted to make my participants’ voices clear in my data analysis through using direct quotes from them, and the data interpretations reflect participants’ experiences and emotions.

Furthermore, being insider researcher plays important role in reflexivity. There are a variety of definitions for insider-researchers, generally insider-researcher are those who choose to study a group to which they belong, while outsider-researchers do not belong to the group under study (Breen, 2007). This insider role status frequently allows researcher more rapid and more acceptance by their participants. Therefore, participants may typically be more open with the researcher so that there may be a greater depth to the data gathered (Breen, 2007). I consider myself as an insider researcher as I share context, language, gender, culture, being mothers of children with ASD and experiential base with the study participants (Merrian et al., 2001).

The key advantages of being insider researcher are understanding the culture being studied and establishing rapport with participants to promote telling the truth. In seeking policy dynamics, insiders may see things differently to outsider, with implications for the data collected and interpretations. As explained by Merrian et al. (2001, p. 411), “being an insider means easy access, the ability to ask more meaningful questions and read non-verbal cues, and most importantly, to be able to project a more truthful, authentic understanding of the culture understudy”. In general, the insider researcher has a great deal of knowledge, which takes an outsider a long time to acquire. The insider-researcher generally knows the policies of the institutions and the context being studied. For example, I know that the process of diagnosis, my pathway was different of that of other mothers in Oman. It was particularly useful for persuading the participants to give better explanations for the process of searching for places for their children with ASD. The insider researchers have the “ability to ask meaningful questions and read non-verbal cues,” as well as the ability to “project a more truthful, authentic understanding of the culture under study” (Merriam, et al., 2001, p. 411).

Being an insider helped to get sufficient data from my participants and to discuss all issues without the focus of wanting to please me. In addition, the importance of being insider is to have participants in which they are less reserved in participating and narrating the events of their stories. I found that many participants reacted positively, and they were willing to participate because they felt that we share similar characteristics as we are mothers of children with ASD. In addition to the benefit of being insider, I also followed certain steps to have more trust from participants.

- I have to make the purpose of the research and data tools clear to the mothers.
- The mothers were told that they have the right to ask questions regarding the research and the data collection tools.
- The researchers were informed and given the right to withdraw from the research anytime. They were also informed in advance that they have the choice of recording or writing their narratives as well as informing them about recording the interviews.
- Their real names will never be used in any of the data presented in the research.

As insider researcher, I needed to be aware of the problems associated with being an insider. For example, the greater familiarity with the context can lead to a loss of objectivity and may lead to make wrong assumptions about the research process based on my prior knowledge. “Insiders have been accused of being inherently biased . . . the outsider’s advantage lies in curiosity with the unfamiliar, the ability to ask taboo questions, and being seen as non-aligned with sub-groups (Merriam, et al., 2001, p. 411).

Being an insider/outsider researcher is also more complex than I anticipated because I expected to be more of an insider than outsider in some areas such as being Omani mother of a child with ASD. However, I found myself as an outsider in other areas such as my experience of diagnosis may not be the same as other mothers in the study. I had the experience to go to England, which may make me an outsider. In fact, I might be an indigenous outsider because I “studied for a doctoral degree outside of (my) own culture, would also fall into this category” and according to Meriam et al. (2001, p.412) “age, gender, social class and education rendered them less of an insider than they had anticipated.” Therefore, I attempted to benefit from my own perspective to build up better understanding for the research topic.

Insider researchers may have to work at impression management to establish respect and avoid a power struggle with participants. An important fact to remember is that “during fieldwork the researcher’s power is negotiated, not given” (Meriam et al., 2001, p. 409). Insider researcher may therefore choose to present themselves as co-investigators or advocates in an attempt to minimize the power differential between themselves and the research participants (Breen, 2007).

One of the key issues in this study is the power as a researcher, which is I am aware of but I have to negotiate it in the research process (Meriam et al., 2001). Mothers considered me as a wise and more knowledgeable mother as I was doing my research in context different than theirs and considered to be more developed than Oman. However, my power as a researcher was negotiated by determining what information were shared about their experiences. In doing the study, mothers’ interest was centred on what I would do with the information I gathered and how would their stories help in changing policies in Oman with regards provisions for children with ASD.

4.9.3 Research methodology constraints

Some issues arose in the use of different methods. For example, in the story narration phase, some mothers provided very limited information, and some of them did not follow the prompts that were provided. The story narration guide had been piloted and I was not with the participants when they wrote or recorded their stories.

The building-rapport days in Phase 3 did not provide me with what I anticipated. I thought that I would not disturb the nature of the mother and her child's interaction. However, for the three mothers, my presence clearly affected their days, as the mothers were busier in their conversation with me than with taking care of their children, thus making the day untypical rather than typical. This could originate from the reasons for their motivation to accept me in their day, which varied from one mother to another: for example, Fatin wanted to show her work with other children with ASD. This affected the findings, as I was looking at the strategies that mothers were using with their children with ASD and their lives with them, which were not clearly observed.

4.10 Ethical considerations

Ethical considerations are essential in any research and should be a concern for the researcher (Punch, 2014). In order to carry out this research, I followed the ethical guidelines for educational research set out by the University of Exeter Graduate School of Education at every stage of my research (see ethics form in Appendix 8).

4.10.1 Assessment of possible harm

Corbin and Morse (2003) identified interviews can cause psychological harm and emotional distress to the participants, especially if the topic area is sensitive or distressing. As it was mentioned in the ethical approval (see appendix 8), ethical research design and execution aim to both put participants at their ease and avoid making excessive demands on them. In advance of data collection, I have a responsibility to think through my duty of care in order to recognise potential risks, and I was prepared for it to minimise and manage any distress or discomfort that may arise. I immediately reconsider some actions occurring during the research process that appear to cause emotional or other harm, in order to minimise such harm. The mothers of the children with ASD who participated in the study are vulnerable, then my responsibility as a researcher was greater in order to protect their wellbeing.

Due to the sensitivity of the research topic, there were potential stress occured in the story narration, interviews, and building-rapport days. In Phase 1, there was no intervention from the researcher into the construction of the stories, so I would not know if this phase would affect their emotion or not. However, in the follow-up interviews, the researcher was welcomed to constructively intervene when necessary because the topic was very sensitive: for example, mothers explaining the extent of the difficulty they were facing with their children with ASD.

As a researcher, I need to take into consideration mothers' attitudes towards the condition of their children, as they may feel guilty about this and they may have a subconscious feeling that they were responsible in some way, for any reason. They may have feelings of anger about enduring this burden and – most probably – they may be concerned about whether what they were doing was in their children's best interests.

Therefore, in order to minismise the harms, I prepared and offered the mothers with some people to contact and the benefits available for them. I have informed a psychiatrist in Hospital about my research, who has agreed to me passing on their details to mothers who may need further support (see Appendix 8). The fact that I am also a mother of a child with ASD, put me in a good position to provide this information for them. "Research that is conducted by sensitivity… becomes a process with benefits to both participants and researcher (Corbin & Morse, 2003, p. 335).

4.10.2 Access and acceptance

Before commencing the study, ethical approval was obtained from the University of Exeter Graduate School of Education Research Ethics Committee (see Appendix 8). This was followed by obtaining access to mothers by getting permission from an organisation working with mothers, the Oman Autism Society. I wrote a letter in Arabic in January 2018. The letter explained the purpose of my study, the different research phases and the data collection methods, and also listed all the participants who were expected to take part in the study. An information sheet and consent form were attached to the story narration form that was requested from the mothers. The Oman Autism Society agreed to support me in accessing the mothers.

4.10.3 Informed consent

Written consent was obtained from all participants (mothers) to indicate their agreement to be involved in the study. All the information for the participants was presented in the consent form and information sheet (see Appendices 9 & 10). Full information about the nature of the study and the high level of confidentiality was clearly ascertained. I also included the consent form, a description of the research project, the purpose of the study, the three phases in detail, and detailed information about data protection and confidentiality.

Participants were assured that all their individual comments would be anonymous and there would be no identification of them from the data analysis. When sending their recorded/ written stories they also sent their signed consent for Phase 1. Moreover, participants' permission was granted to audio-record the interviews before starting them in Phase 2. All of the participants needed to sign consent forms prior to starting the building-rapport days, on their behalf and their children's behalf. They were assured that they could remove any portion of the stories or interview conversation at any time during the study if they deemed it to be too sensitive or inaccurate to be included in the study. I asked this after they had /sent their stories and after the interview. One participant, at the end of the interview, asked me to remove certain parts as she felt it was too sensitive for her.

4.10.4 Issues of anonymity and confidentiality

The meaning of anonymity is that the participants' information should not identify them, and confidentiality refers to participants' right to privacy, and assurance that their connection to information should not be known publicly (Punch, 2014). In this study, confidentiality and the protection of participants' identity were assured during data collection and data analysis. Data were solely used for the study and were stored securely in my laptop with a password locked document, to ensure privacy. Participants were assured of confidentiality and privacy, and that data would only be used for the purpose of the study. Although the story narration phase included demographic data, participants had a choice as to whether to include their names or not (see Appendices 9 & 10). During analysis and presentation of the data, real names were replaced by pseudonyms, and all identifying details were removed to ensure confidentiality. Raw data were only available for the researcher to support the research process and were not shared with other agencies or institutions directly.

4.11 Summary of Chapter four

Exploring the lives of mothers of children with ASD, and their educational choices and decisions, was the aim of the current research, which adopted the narrative paradigm. Thus, there were different phases to collect data, in order to provide an answer to the research questions. To provide an in-depth understanding of the mothers' experiences, perceptions, and feelings, the study conducted three phases of data collection: story narration, interviews, and building-rapport days. This chapter detailed the research design, the data collection, the data analysis methods and procedures, as well as issues related to quality and ethical considerations. The following chapter will present the findings of the current study.

Chapter 5: Findings and Analysis

5.1 Introduction

This chapter presents the data and findings from the three phases of data collection: story narration, interviews and building-rapport days. It shows that the different data sources are interrelated and how the findings from each source link together to form themes. The chapter starts by presenting mothers' stories from Phase 1 (story narratives), the second section summarizes mothers' stories from Phase 2 (interviews), the third section analyses Phase 3 (building-rapport days), and the final section presents a cross-case analysis covering all three phases. The summaries of the mothers' interviews and the findings of the cross-case analysis are presented according to eight themes (as explained in Chapter 4): early signs and diagnostic struggles; finding an educational placement for their children with ASD; mothers' strategies to support their children's development; mothers' perceptions about their lives with a child with ASD; mothers' feelings about their children's development; mothers' perceptions about the services available for children with ASD; family and societal support; and hopes and concerns about the future. The cross-case analysis section is also organised by categories and sub-categories in the data.

5.2 Mothers' summaries from Phase 1(Story Narratives)

This section presents 14 summaries from the mothers' story narratives, from the total of 25 story narrations. These 14 summaries were selected for inclusion here because these mothers were participants in Phase 1 only. The other 11 mothers were also participants in Phase 2 and their interview data is presented in 5.3 below, whilst their story narration summaries are in Appendix 6. This is intended to avoid overlap and repetition. The themes taken from the 25 mothers' story narratives will be used in the cross-case analysis section (5.4).

Anfal is the mother of Khamis, a child with ASD. She had not heard the word "ASD" before her son was diagnosed. Khamis' mother said that her family is supportive and cooperative in taking care of Khamis. Anfal tries to develop her son's skills at home by using games and stories. Though Khamis is independent in most life skills, such as going to the toilet or eating, and is able to read and write, Anfal struggled to find a place for him in a mainstream public school in a mainstream class. He was in a public special school, but she moved him recently to a mainstream public school in a special class for children with special educational needs (SEN).

Ibtihal is the mother of Yahya, an 8-year-old boy diagnosed with ASD. She questioned his condition at the age of 16 months when he developed atypical behaviours such as hyperactivity, problems in speech, repetitive actions, and hysterical laughter or constant crying with no reason. Ibtihal suffered from depression, which led her to start taking medication. She faced accusations from her family about negligence and carelessness towards her son, and she did not get support or help from her family. She used many strategies to develop her son's social, life and academic skills. Her son was rejected by many schools, but she managed to find a place for him in a mainstream public school with neurotypical children.

Jori is the mother of Mishari, a child with ASD of nursery- age. Jori described her son's level of ASD as moderate. She travelled abroad to find the answers for her son's delay in development and behaviour. She was shocked that her son needed intensive training and rehabilitation in order to support his speech skills. She thinks that she is at the beginning of her journey with ASD. She trains her son at home, and he also goes to a private special school.

Jumana is the mother of Arif, who is in a mainstream private school. She managed to develop Arif's social, life, and academic skills by encouraging him to mix with other children. He is now studying with other neurotypical children. Jumana developed her knowledge about ASD by searching the internet and social media.

Maha, thinks her son, Jamal, is a clever 9-year-old boy. Maha did not have any idea about ASD. She decided to use different strategies to 'treat' and 'educate' her son, such as using medication, diet therapy and functional therapy. Maha did not find support for her son from any governmental institutions and was rejected by schools. Then she found a place for him in a public special school, which, Maha thinks, supported Jamal's development. She said that her family is very supportive and considerate.

Maria is the mother of Adnan. Maria is a working mother. She thought that leaving her son in front of the TV caused his ASD condition. She used some strategies to develop her son's social and academic skills, such as using pictures. Adnan is in a private special school for children with ASD. Maria thinks that Adnan has developed greatly and learned to read and write.

Mayada is the mother of Al-Wraith, who was diagnosed with ASD. She could not find the answer to her questions about her son's condition in Oman and preferred to take him to an Asian country to seek a 'cure' for his condition. Al-Warith was rejected by many places in her town, and she could not move to the capital city to provide him with intensive training. Though Mayada managed to enrol her son in a public special school, she feels this is not helping him.

Nirmin is the mother of Al-Molham who was diagnosed with ASD. She was shocked and disappointed when she found out about his condition. Nirmin enrolled him in a private special school. She thinks that the school assisted his progress as well as his speech. She thinks that the community has been unfair with her son and her family has never accepted him. This caused her to lock herself in at home and to feel tired, sad and isolated.

Njood is the mother of Salman, diagnosed with ASD. She did not have a precise diagnosis, but she felt that there was something in her son that she did not understand. She enrolled him in a private special school at the age of seven. She thought that his development was very slow. Salman was rejected by private schools, but she managed to hire a private teacher in the mornings at home.

Rafif is the mother of Hatim. She started with her son without a diagnosis. She did not send him to any school and she trained him at home. She tried different ways that she found on the internet, and she worked hard to adapt and change strategies to meet her son's needs. She said that she was sad and depressed. Rafif's family was supportive, but there were some people around her who did not understand ASD.

Rahaf is the mother of Mansoor, who is the fourth child among his siblings. Rahaf questioned his behaviour and she managed to get a diagnosis of ASD. No words could describe her feelings about this, but she had confidence that she would help her son. She enrolled him in a private special school to develop his visual and social skills and to overcome his sleep problems. Mansour is still young, but Rahaf always has concerns about his future.

Razan is the mother of a teenage girl, Khamail, who had a diagnosis of ASD when she was two years old. Razan seemed to think that her daughter was affected by an 'evil eye' that changed her from a neurotypical daughter to a daughter with strange behaviours. She was confused and shocked because she had been told that Khamail had a brain deficit. She enrolled her in a private special school and cooperated with the specialist there to develop her daughter's skills.

Samaher is the mother of two children with ASD. Sami (male) is 14 years old and Samia (female) is 8 years old. She did not have a clear diagnosis for her son, but she was able to enrol him in a mainstream public school and he is now in year 5. He missed two years of school, but he is doing well now. Samaher managed to enrol Samia in a public special school, but she felt that her condition was getting worse, so she decided to remove her from school. She teaches her daughter at home using photos.

Zulfa is the mother of a primary-school-aged boy, Amar, diagnosed with ASD. She supported her son's development through diet therapy, speech therapy, vocational therapy and intensive home care. With a struggle, she was able to enrol him in a private mainstream school. Now, she thinks that she succeeded in developing her son's skills to help him be a typically growing boy.

The 25 mothers who wrote or recorded their stories, varied in their backgrounds, their education, the ages of their children with ASD and their ages (see Appendix 6). Despite this, it seemed that most of them noticed that their children with ASD developed unfamiliar behaviours not seen in their peers, which caused them to be concerned. As, a result, they attempted to find answers to their questions about their children's behaviours. They each seemed to face challenges, as well as to think about strategies and places that might help them. They also narrated some actions they had attempted when they were looking for a diagnosis for their children, or for their education. This will be explored in depth in section (5.5.1).

5.3 Mothers' summaries from Phase 2 (interviews)

The following section includes summaries of each mother-participant's interview, constructed as described above (see Chapter 4, section 4.9), from all the recorded, transcribed interviews, only three of which were translated. The interviews focused on the experiences, perceptions and feelings of the mothers when making decisions and choices for the education of their children with ASD. The summaries are organised by themes that were developed through the data analysis processes (not all themes will be presented for each mother, because some were not mentioned by some mothers). There may be many ideas included under each subheading, but there will be a cross-case analysis later in this chapter. There will also be the use of quotations from mothers' interviews to highlight mothers' experiences about their child with ASD.

5.3.1 Aseel and her son Marwan

Aseel's son, Marwan, was 9 years old when I interviewed her. He was going to a public special centre for children with special needs. Aseel has two more children besides Marwan.

Purpose of education

Aseel described her son as *"different"* from his peers, so he needed *"rehabilitation"* and *"intensive life-skills training"* such as toilet training, feeding himself and getting dressed. She defined education for Marwan as aimed towards being independent *"in life skills"* and to *"learn life skills"* (I:p.1).

Finding an educational placement

Aseel's decisions about her son's education were affected by three main things:

Marwan's characteristics; the services available for children with ASD in her town; and the facilities available in the centre for children with ASD.

She could not initially decide whether to seek a place for him in a mainstream school because her child *"was hyperactive, was not able to depend on himself, was still in nappies, and was unable to go to the toilet by himself, and because Marwan is not able to speak or to understand"* (I:p.2). For Aseel, the choices were limited because she lives outside the main cities. Once she decided that a mainstream school was not for her son, her choice was between two options: a private special centre or a public special centre. Her first choice was the private special centre for children with ASD; however, once he started attending this centre, his condition was affected negatively, and he *acquired negative behaviours such as biting and flapping"* (I:p.2). Though Aseel thought that the private centre was not bad, she felt that the *"specialists were not able to deal with Marwan" and she said, "I did not feel that my son was developing."* (I:p.2). She stated that she had noticed that many children benefited from the private centre, but she decided to transfer Marwan *"to another centre funded by the government"* (I:p.2). Her decision was made after she had consulted one of her sisters, who was working in this centre and suggested that she would look after Marwan. This made her feel more *"comfortable with [her] decision."*

Aseel's strategies to support her child's development

Though Aseel tried to support her son's development, she thought that she was unable to do this because, *"he did not interact with [her] strategy, the same way he interacted with the specialist in the centre (because he was scared of him)."* Alternatively, she thought that she *"might be spoiling [her] son in a way that he did not respond to [her] way of training"* (I:p.3). As a result, she thought that the best way to support her son was through *"continuous contact with the specialist in the centre."* In addition to that, Aseel was convinced that her son was affected by an 'evil eye,' which caused his condition, saying: *"I know that he was affected with an evil eye because he was fine for the first two years of his life"* (I:p.2). She therefore frequently took Marwan to traditional healers. She also believed that vaccinations caused her son's condition. Aseel carried out some activities with Marwan: these were spontaneous rather than structured, such as *"playing* *games, life-skills activities, and taking him to the park to play with the children or going to the sea to play with his brothers”* (I:p.4).

Aseel’s perceptions of services available for children with ASD

Though Aseel thought that the services were limited when Marwan was young, she noted that currently there *“were many centres that could support children with ASD”* (I:p.5). Aseel thought that the Ministry of Social Development (MOSD) was doing well to support the development of children with ASD because they had provided public centres for SEN children and children with ASD. These centres were equipped with *“good specialists and staff,”* and she said that they also *“conducted regular workshops for parents of children with ASD”* (I: p.4). She was not aware of any services available for children with ASD from the Ministry of Education (MOE). Although there were some services available in Oman for children with ASD, Aseel wished to *“go to a place outside Oman where [she] could see Marwan improving and depending on himself in life skills,”* and as a mother, she *“could learn ways to deal with [her] son and develop [her] decisions on the education of [her] son”* (I: p.8).

Family/community support

Aseel thought that her family was supportive from both sides – her family, and her husband’s family – because she was a working mother; they took care of her son when she was at work.

Hopes and concerns

Aseel hoped that her son could be a ‘normal’ child as he used to be when he was two years old and become independent in life skills. Her main concerns were related to what would happen to her son if she died. She advised mothers of newly diagnosed children to *“to be accurate about [the] diagnosis and to find a good centre”* (I:p.5).

Summing up Aseel’s experience, she generally felt happy with Marwan’s development, though, at the time of the interview, she was *“experiencing drawback in [her] son’s condition.”* She did not regret any decisions she had made for him, but she wished to take him outside the country to find better services. Aseel commented: *“after all, Marwan is my son, and I would do what a mother should do”* (I:p.8).

5.3.2 Athari and her son Mustafa

When I met Athari, her son, Mustafa, was nine years old. He was diagnosed with ASD at the age of 5 when she was studying in the UK. He was going to a private mainstream school at the time of the interview.

Purpose of education

Athari defined education for Mustafa as being the development of his *“concentration and understanding”* and did not mean “*reading and writing*” (I:p.2). Athari did not want her son to *“develop academic skills, to get high marks, to go to a college or to get a degree,”* because he *“did not understand the meaning of school, the meaning of education or learning”* (I:p.1,2). Her main focus was on *“developing his social and verbal skills”* (I:p.5).

Finding an educational placement

In Oman, she was trying to find an educational placement for Mustafa. Compared to the schools she had found in the UK, there was no school in Oman that satisfied her. Athari was looking for a school that *“would help [her] son to meet his special needs”* and *“develop his special and verbal skills,”* more than focus on developing his *“academic skills”* such as reading and writing (I:p.5). She was visiting schools and centres and spending a full day with her son in a school. Then she would later decide whether the school was *“suitable”* for her son or not. Athari faced *“rejections from school”* as well, and she found *“that many schools did not understand the meaning of integration”* that she was looking for. She found that there was a *“contradiction between the school’s description of integration and [their] application [of it]”* (I:p.4). She finally managed to find a private mainstream school to enrol him in.

Athari’s strategy to support her child’s development

Athari’s strategy to help her son was to develop *“the same plan for the three parties (home, school, centre)”* (I:p.5). She also selected the current school because they had *“a shadow teacher* [see glossary] *who would support [her] son’s development during the school day.”* Athari had a *“housemaid and a driver”* who took Mustafa to school. She hired a driver because *“the school bus took a long time to bring him back from school,”* and the housemaid because she *“did not trust the driver”* (I:p.11). Athari had an intensive education plan for her son, so he *“was in school in the morning; he had a swimming session in the afternoon and one-to-one sessions in the evenings.”* She continuously *“contacted the teachers in the school, and the specialists in the centre”* (I:p.5), so they *“would be on the same page as each other to support [her] son.”* The private centre *“used a notebook to follow up what was given at the centre”* (I:p.5). In this notebook, Athari felt that she knew *“his needs more than the teachers and the specialists,”* so she alerted and modified the tasks using her knowledge (I:p.5). She also requested the teacher not to give Mustafa *“homework except weekends”* (I:p.11) because he had an intensive programme during the weekdays.

She used the strategy *“of love and cuddle[s] because these were more effective than being strict with him”* (I:p.7). She also restricted *“the use of phone except for reinforcing good behaviour”* (I:p.8). According to Athari, she had established *“rules for my children at home”* (I:p.11), which helped Mustafa to be independent in life skills.

Mothers’ perceptions of the services available for children with ASD

Athari was *“active in mothers’ society,”* and she was *“fighting for children with ASD’s rights.”* One of the main fights was to get places for children with ASD in mainstream public schools. However, she did not feel that she could *“trust any public mainstream schools”* (I:p.12). According to her, *“teachers were not prepared for understanding children with ASD, school buildings were huge, teachers were overloaded with school duties, the school size was not suitable for children with ASD and teachers were not cooperative [in] deal[ing] with a child with ASD”* (I:p.12).

For the mother of a child with ASD, if she had to choose between a public and a private mainstream school, the decision would depend on the region. *“In the capital city, there were varieties of schools to choose between, but in other* *regions, choices were limited”* (I:p.12).

Athari insisted that, “*there were not many services available for children with ASD in Oman, there was some funding for the rehabilitation session, but these sessions were not enough to develop children.”* In general, the MOSD provided *“some services for children with ASD, but these were not enough”* (I:p.13-14). However, the MOE was *“doing nothing”* (I:p.14). There was *“no support for children with ASD and their families; people in the ministries did not understand their jobs, because their responsibilities require social and emotional involvement to consider and provide parents with their needs, but few employees were sincere in their job”* (I:p.14).

Athari also thought that the centre that her son was in did not have *“the best teachers my son could have”* because they wanted *“to jump from one goal to another without mastering it.”* There were always conflicts between the mother’s *“plans and the centre’s plans with regard to the use of electronic devices”* (I:p.7).

Family/community support

Athari found support from her immediate family, husband, elder son, and the housemaid (I:p.9,10). They took turns and shared responsibilities in taking care of Mustafa.

Hopes and concerns

Athari hoped that Mustafa would be *“independent”* and her *“biggest dream was just for him to depend on himself”* (I:p.15). With regard to her concerns, Athari expressed her belief in God as she said: *“I am leaving this to God. I cannot change the future. I have some fears, but I try to think about my day and not more than that. Moreover, since Mustafa has developed, I thank God for this everyday”* (I:p.16).

To sum up, Athari felt it was important to *“read about autism.”* She also advised mothers to play a big part in their children’s education. Generally, she thought that she was *“able to manage stress,”* and she was *“capable of facing* *challenges.”* Though she was *“not sure about the future, [she] always focused on the present and not the future” (I:p.12,13).*

5.3.3 Fadwa and her son, Affan

Fadwa’s son was Affan, who was 10 years old when I met her. He was attending a private special centre for children with ASD. Fadwa had three other children besides Affan.

Purpose of education

Fadwa described ‘education’ as *“learning, rehabilitation, learning new manners and developing skills”* while the meaning of ‘cure’ was *“using medication”* (I:p.1). Education, to Fadwa, does not always mean *“reading and writing”* (I:p.1). Fadwa compared Affan’s education to his siblings’ education as *“different paths”,* but she had plans to *“train all of them, including Affan, on certain skills such as swimming, karate, football”* (I:p.1).

Finding an educational placement

Fadwa had changed centre many times; she had changed it *“4 times in 8 years because these centres were continuously changing the staff”* (I:p.3).

Fadwa had certain criteria when she chose each centre for her son. She detailed those that were related to her satisfaction about the centre. She *“would visit the centres (three times at least),” and* she *“would sit with specialists and would discuss with the specialists what [her] son needs.”* Her choice would be to go for the centre that had *“similar ideas about rehabilitation as what [she] had in [her] mind”* (I:p.3).

There was another consideration mentioned by Fadwa concerning the centre in that her decisions depended on Affan’s development. At the beginning of *“his life, [her] main focus was on his physical disability. As soon as he started walking and running, [she] moved to work with developing his speech and life skills”* (I:p.4).

Fadwa thought that her decisions were affected by her family, meaning her *"husband, siblings, father, and other family members"* (I:p.4).

Fadwa's strategy to support her child's development

Fadwa had initially had an intensive plan to develop her son's skills. This plan included *"speech therapy, swimming, counselling, vocational therapy, occupational therapy and physiotherapy"* (I:p.2). These therapies *"affected Affan negatively, there was no development, and [her] son rejected all the specialists,"* and he did not want to work with any specialist (I:p.2). This made her change her plans, but at the same time, she did not want to stop everything at once. So, she *"replaced physiotherapy and occupational therapy with water therapy, [she] changed the centre, changed the hospital to another one, reduced the one-to-one training hours, and used pen and paper instead of using puzzles"* (I:p.2). In addition to this, she played a significant role in her son's education through her *"continuous communication with the staff"* (I:p.3), and *"continuous involvement in setting plans for Affan"* (I:p.3,4).

Fadwa had a training plan for her son at home. She always insisted *"[on being] creative to achieve the same goal differently, to use the items from the environment and to involve his siblings"* in developing his life skills and taking care of him. For Fadwa, it was essential to *"involve neighbours as well and to explain to them"* her son's condition because she found that *"many times, they helped to stop him when he ran away"* (I:p.4).

At home, Fadwa developed *"group play in order to develop Affan's skills such as sharing responsibilities, tidying up the house, doing some housework, or even having a barbecue"* (I:p.6). Whenever she was training Affan, it was important that he was calm during the sessions because he would never benefit if he *"was having tantrums"* (I:p.6).

Fadwa's perceptions of the services available for children with ASD

Fadwa thought that there were some services, *"but not many; there were limited health services. Some integration classes for children with ASD were unsuitable because the staff working there were unqualified, and the class atmosphere and the plans were not suitable"* for children with ASD (I:p.6). According to her, there were *"no support services for families of children with*

ASD" (I:p.6).

Family/community support

Fadwa found that *"explaining to [family and neighbours] [her] son's condition"* was very important to find the support she needed. She also trained *"his siblings to take care of him"* (I:4). By doing this, she expressed positive feelings about the support from her community.

Hopes and concerns

Fadwa hoped that Affan would learn a craft because she *"would not always be there for him, so [she] wanted him to depend on himself and be productive."* She also hoped that one day he would, *"have his own family and have kids."* Her biggest hope was that he would *"be independent and have an income"* (I:p.7). However, her biggest worry was that Affan would always *"be dependent on his siblings, who might be busy with their own lives"* (I:p.7).

To sum up, Fadwa thought that mothers needed to *"accept their children"* as they are*, "be patient and determined, to be positive and to start rehabilitating him as early as possible"* (I:p.5, 6). Mothers should also *"trust themselves, trust their decisions, and learn from mistakes"* (I:p.8).

5.3.4 Fatin and her two sons, Khozam and Hassan

Fatin had two children diagnosed with ASD, Khozam (10) and Hassan (4). Fatin had conducted much work to help her two children, as well as support other mothers of children with ASD, by teaching children with ASD at her home and finding funds for them from local authorities. At the time of the interview, her elder son was studying in a nearby country, and she was taking care of her younger son. Therefore, most of the interview was about the younger son.

Purpose of education

Fatin thought that the purpose of education for her children was to *"teach them life skills*" and to support their speech development (I:p.3). She felt that her children *"do not need academic skills"* as the most essential education was *"to meet their needs."*

Finding an educational placement

Fatin's second son was only 4, and he was initially in an expensive nursery. She felt it was better to change the nursery to a cheaper one and to use the extra money for additional sessions such as *"swimming, horse riding sessions, extra speech sessions, socializing with normal children, and preparing strategies to teach him good manners"* (I:p.4).

Fatin's strategy to support her child's development

Fatin had developed home activities to support her child's skills such as *"drawing animals or items, mimicking voices of animals, taking him to the zoo and toilet-training him"* (I:p.1,6). According to her, her social activity was inviting other children to her house as part of her plan to support her child through the *"use of group activities"* (I:p.4). She described it as essential that any child's development be followed by a *"continuation of the tasks at home"* (I:p.6). She found out that strategies using *"love and cuddles, life skills training, and one-to-one activities*" (I:p.6) were effective in developing her child's skills.

Fatin's perceptions of the services available for children with ASD

Fatin thought that *"nothing was available for them in comparison to other countries"* (I:p.8). According to her, there must be strong demand from parents of children with ASD to *"request services from the government"* and *"parents needed to have a voice about their children's rights"* (I:p.8). She said that there were *"few schools that would accept children with ASD"* (I:p.8). She thought that there should *"be trained specialists"* available (I:p.9). With regard to Fatin's involvement in her children's programme, she found that she was not *"allowed to interfere in changing the programme for her children"* (I:p.6).

Family/community support

Fatin thought that she needed family support because it was difficult for her to deal with *"her child alone, and she needed her husband and the housemaid's support."*

She complained about Omani society's negative attitudes to children with ASD, and said that there was *“no cooperation with parents”* (I:p.3). The community *“treated children with ASD negatively”* (I:p.3). She described the way that the community looked at ASD as *“a kind of insanity.” “They thought children with ASD were crazy, and they did not understand the meaning of ASD”* (I:p.4). Regardless of the community’s negative attitude, Fatin thought that she was *“satisfied about [her] son and ignored other people’s reactions to [her] son’s behaviour in public places,”* because her son’s *“development was more important to focus on” (*I:p.2, 4).

Hopes and concerns

Fatin hoped that one of her children would, one day, be *“a doctor, and the other one would be a dentist” (I:p.11).* She hoped that *“community awareness would be increased among those in Omani society.”* She also described her hopes that, one day, there would be *“clubs for children with ASD, places that support the children’s creativity, and training for parents of children with ASD.”* She also thought that *“mothers needed to be shadow teachers for their children”* (I:p.11).

Fatin thought that, regardless of the challenges that mothers encountered, they had to start as early as possible rehabilitating their children because *“the earlier they start, the earlier they would get results”* (I:p.5). Mothers needed to understand that ASD was *“not a disability”* and to *“accept ASD in [our] lives”* (I:p.5).

5.3.5 Narjes and her son, Amjed

Narjes was retired when I met her. Amjed was seven years old. She had moved to the capital city in order to find *“a good centre”* for him. She had three other children.

Purpose of education

Narjes emphasized that education for her son means being *“independent”* in taking care of him and his education was *“different from his siblings”* (Narjes, I: 2).

Finding an educational placement

Narjes thought that Amjed’s education was *“different from his siblings”* because of his condition (I:p.1). Narjes’ choice of centre depended on *“recommendations from others, distance from home and the specialists’ abilities to deal with [her] son”* (I:p.5). These factors caused her to change centres several times because there were *“not enough workers and specialists in the centres and no obvious development in Amjed’s condition”* and Narjes felt that *“the centre was unable to work with him”* (I:p.5). Before she decided on a centre, she asked *“mothers about the centres, and she attended workshops conducted by the centres to introduce their services”* (I:p.6). Narjes felt the *“transfer between centres affected Amjed negatively”* (I:p.6), but she was looking for a centre that *“would support his development.”*

According to her, all the centres in Oman were the same *“because they followed the same system.”* She believed that *“there were good and bad specialists in each centre,”* and that *“good specialists create a good reputation for a centre.”* However, in general, *“all the centres followed the same rules from the MOSD, and all the centres exploited parents of children with ASD”* (I:p.7). According to Narjes, because she had *“continuous communication with the specialists in the centre, [she] was unable to comment on the specialists’ work, though [she] was not satisfied with their work”* (I:p.5). It was expected that this would help her to be able to comment on their work. However, she stated that this made a stronger relationship with the specialists that did not give her the ability to comment on their work.

Therefore, Amjed went to *“a centre in the mornings and had a specialist at home in the evenings”* in order to accelerate her son’s development. Her choice of *“specialist depended on trust”* (I:p.3). If she trusted a specialist, she *“would ask him to come to [her] home.”* Her *“choices depended on their qualifications, recommendations from others, and their willingness to come to [her] home”* (I:p.4). Many times, Narjes faced difficulties with bringing a specialist home such as *“these specialists would ask for a place to stay, and daily meals”* (I:p.4).

Narjes’ strategy to support her child’s development

Narjes was continuously *“thinking about the ways that [she] would help [her] son’s development,”* and one of her thoughts was to *“bring a specialist home*”

(I:p.1). She described her strategy to help her son as *“intensive,”* as there was *“no weekend, no summer holiday, and no breaks for Amjed”* (I:p.3, 4). At the time of the interview, she was *“looking for a boarding school”* (I:p.4). Narjes also used other strategies at home to develop his skills, such as *“encouraging him to go out with his brother and father”* (I:p.10). If the family was going on a trip, they *“had to plan the trip and to have short breaks in order to deal with his tantrums,”* because Amjed would *“not tolerate long trips”* (I:p.12).

For Narjes, the *“financial factor was not a reason that would stop [her] from choosing teachers or schools for Amjed”* (I:p.3).

Narjes’ perceptions of the services available for children with ASD

Narjes thought that there were no *“services available for children with ASD”* in Oman (I:p.2). She described the difficulty of moving from her town to the capital city in search for a better service. She enrolled him in many centres, and they were *“all the same, or maybe each one was worse than the one before”* because she thought *“that they were constrained by the [Ministry of Social Development] rules” (*I:p.6). The centre that she *“was looking for did not exist in Oman”* (I:p.13).

Family/community support

Narjes had support from her family. Though she thought that she was *“the one who should make the decisions for Amjed,”* she always *“discussed and arranged plans as a family”* (I:p.9).

Hopes and concerns

Narjes hoped that Amjed would *“be independent in his life skills”* (I:p.12). She firmly believed that *“one day, [her] son would speak, because he hummed songs, so he understands them”* (I:p.13). Though she did not want to think about the future, Narjes was in *“a continuous worry”* about her son (I:p.9).

To sum up Narjes’ story, she advised mothers to *“start with early intervention for their children, to have a clear diagnosis, to find a good centre for him/her,* *and to find a good specialist to work with him/her."* Narjes thought that mothers needed *"to be realistic in their dreams and to trust God"* (I:p.3).

5.3.6 Shahad and her son, Mojahed

Mojahed was 14 years old when I interviewed Shahad. She described him as a *"hyperactive and not a verbal child"* (I:p.5). Shahad had one son and four daughters besides Mojahed.

Purpose of education

According to Shahad, her first dream when she had Mojahed was that *"he would join a mainstream school"* (I:p.1). She thought he would *"read, write, colour, and hold a pen"* (I:p.3). However, Mojahed *"was totally different"* to his siblings (I:p.3). He *"was not capable of public education"* (I:p.1). He needed *"to learn how to drink, to eat and how to get dressed"* (I:p.3). Education for Mojahed meant focusing on *"developing his skills, changing his behaviour, and teaching him life skills"* (I:p.3). He needed *"special education, occupational therapy, and physiotherapy"* (I:p.1).

Finding an educational placement

In the beginning, Shahad *"did not know what he needed in order to find a school to suit him.*" She *"did not know that he needed special care,"* and she did not "*know where to take him*" (I:p.1). However, she knew that *"mainstream learning was not suitable for [her] son"* (I:p.3).

Shahad managed to find *"a special centre in the UAE"* (I:p.1) and she enrolled Mojahed in this centre for four years, but after this, they had to *"come back because of family circumstances"* (I:p.2). He *"stayed at home for two years"* (I:p.1). She now had to look for another centre.

Shahad thought that her *"choice would depend on the specialists available in the centre"* (I:p.6). Therefore, Shahad *"visited public special centres, and spent full days in these centres."* There was *"no cooperation from these centres with the families, and [she] did not feel these were suitable or prepared for Mojahed"*

(I:p.7).

There *“was one centre opened with the cooperation of her husband and other parents of children with ASD”* (I:p.2). Shahad thought that this private centre was right for her son, as *“the specialists were very supportive*, *doing their best to help him*, and *working hard with him”* (I:p.2, 9).

Shahad’s strategy to support her child’s development

When Mojahed was in the UAE centre, Shahad learned many strategies through her communication with the school (I:p.1). He had some problems with motor skills, so she tried to support his walking *“by using a piece of tape for him to walk along, preparing a full room for training him and increasing his concentration”* (I:p.1). Shahad explained that it was essential to *“take him everywhere”* with them as a family*,* regardless of whether *“he was crying”* and *“making trouble for them*.” *“He got used to”* moving around, and they were able to “*travel with him four or five times”* on their vacations (I:p.5).

As part of her help for her son, Shahad thought that *“cooperation between the centre and home was important for Mojahed”* (I:p.3). The centre sent *“updates about Mojahed’s development”* (I:p.3). This would help her to *“apply what was done in school”* (I:p.3). Shahad said that Mojahed’s father was the one who *“discussed the plan for Mojahed with the specialists in the centre*,*”* as she was *“busy with other children”* (I:p.6).

Shahad’s perceptions of the services available for children with ASD

According to Shahad, there were *“no services for children with ASD in Oman, except funding and the monthly allowance from the MOSD”* (I:p.7). She also added that nothing was “*provided by the MOE,”* even when she *“offered to be a shadow teacher for her son, they refused and never cooperated”* (I:p.8).

There were public special centres funded by the MOSD, but these were *“not prepared for children with ASD because the centre was crowded with children with other disabilities, the specialists there were not qualified to deal with* *children with ASD."* Even if she *"never found a place for [her] son, [she] would not take him to these centres"* (I:p.7-8).

Family/community support

Shahad found support from her immediate family. Her *"children and husband were taking responsibilities to take care of Mojahed"* (I:p.8). As *"a family, they were cooperative"* in *"helping [her] to take care of him"* (I:p.5, 8).

However, she could not find support from her community, because they *"did not understand Mojahed's condition, and they thought he was a crazy person"* (I:p.4).

Hopes and concerns

Shahad always hoped Mojahed would *"learn to read and write"* (I:p.3). She hoped that he would *"be independent in life skills,"* and that he would *"be a normal child."* Her dream was *"to see him as a normal as possible, to recover from his condition, to go to a mainstream school, to depend on himself, and to understand what was going around him"* (I:p.9, 10).

Her main worries were that he would *"go out of the house into the street, and get hurt"* (I:p.10). Shahad believed that *"it is God's will, and God had not made a disease without appointing a remedy for it, except one disease, namely old age"* (I:p.2).

For Shahad, it was important to *"accept the idea of having a child with ASD,"* and to *"find a centre to support the child's development"* (I:p.9). Mothers needed to understand *"their child's condition"* in order to be able to support their development (I:p.10).

5.3.7 Shojoon and her two daughters, Hoor and Noor

Shojoon had two daughters diagnosed with ASD, Hoor (9) and Noor (5). She also had a younger son.

Purpose of education

Her main plan was to develop *"[her] daughters' mental skills to suit their age"* (I:p.1). She thought that *"education was different from a cure,"* and stated that the purpose of education for her two daughters should be *"to develop their skills to be close to those of typically growing children"* (I:p.1). Shojoon thought it was essential for her daughters that their education met their *"needs",* namely, *"to understand what was going on around them, and to be independent in life skills" and "to help them understand their surroundings, danger, and the difference between right and wrong"* (I:p.1,3).

Finding an educational placement

Shojoon described her two daughters as *"different in specific skills"* such as their *"understanding and response to instructions"* (I:p.1). However, her choices for educational placement were based on *"the availability of the centres"* (I:p.7).

According to Shojoon, she *"benefited from her failures"* with her first daughter (I:p.7). After she experienced some *"successful and unsuccessful decisions"* (I:p.2), Shojoon thought her *"decisions became better."* Her elder daughter moved from one centre to another, while the younger daughter did not experience this.

She could not *"think of enrolling them in mainstream public schools,"* because her "*daughters' characteristics would not allow them to fit into these schools*" (I:p.3). The elder daughter might find *"integration"* easier, *"but the youngest was more connected to mum*." Her instinct as a mother, she said, suggested to her that mainstream schools would not help her daughters. She *"wanted the best for them,"* and they needed *"speech sessions, special education, and behavioural sessions,"* which would not be available in the mainstream schools (I:p.3). However*, "financial problems constrained [her] decision"* about the centres (I:p.7).

Shojoon had experienced three special centres for children with ASD with her first daughter, eventually settling on one centre, which she felt would meet her *"daughter's needs"* (I:p.2). Shojoon talked about her *"involvement in her daughters' education"* (I:p.7), such as *"discussing plans and goals with the specialist in the centre."* Shojoon thought that the centre had helped her daughters as they had *"developed and became somewhat independent"* (I:p.9). However, she would like her daughters' development to be close to that of "typically growing children " (I:p.6).

According to Shojoon, transfer between centres had affected her first daughter (Hoor), *"but it was not negative, because the first move happened when she was very young"* and these transfers did not *"slow down her development"* (I:p.3).

Shojoon's strategy to support her children's development

Shojoon was involved in her daughters' education through *"continuous communication with the specialists in the centre, continually visiting the centre and meeting with the specialists, and discussing plans for them".* She tried to keep *"diaries about [her] daughters' behaviour,"* which helped her when discussing plans with the centre (I:p.2). She thought that her eldest daughter needed more *"pre-school skills, such as holding a pen, and the youngest needed more comprehension tasks"* (I:p.1). At home, she stated that she continuously *"supported their life skills, such as preparing themselves for school, and feeding and dressing themselves*." Shojoon also believed that she needed to train her son to take some *"responsibility towards his sisters"* (I:p.5). She described some strategies to develop her daughters' skills such as *"the use of cuddles and love, cooperation between the centre and her, taking them to the park, taking them to the market, and continuous communication with the centre, with doctors in Oman and with international doctor*s*"* to keep herself up to date with new strategies to support her daughters (I:p.6).

Shojoon's perceptions of the services available for children with ASD

According to Shojoon, *"funding from the MOSD and integration classes in the*

MOE were the only services available for children with ASD in Oman" (I:p.5). Shojoon could only get funding from the MOSD.

Family/community support

Shojoon said that she did not have "*support from her husband*" (I:p.5), stating that he did not share any responsibilities even towards their *"son who needed his father"* and who was *"affected negatively by his two sisters' condition,"* as he was the youngest (I:p.5).

Hopes and concerns

Shojoon's main worries were *"adulthood, because they were girls and their body would change"* (I:p.10). She was always scared that "*people might do something bad to them*" (I:p.8). Her hopes for her daughters were for them *"to be independent"* (I:p.10).

To sum up, Shojoon thought it was essential for mothers *"to accept their children as they were and to do the best for them"* (I:p.8).

5.3.8 Somood and her son, Tariq

Interviewing Somood was not easy for her. I offered to stop the interview several times, but she asked for it to continue without any pressure from me. Her son, Tariq, was nine years old when I met her.

Purpose of education

Somood thought that her son's education should aim to develop his behaviour because he was *"misbehaving, running away, making trouble and snatching food from other people"* and *"his motor skills were not good"* (I:p.4). He was *"screaming, having tantrums, annoying everyone and breaking everything, and being aggressive and violent."* She described his behaviour as if he *"wanted to get out of his body"* (I:p.1). Therefore, the purpose of education for Tariq was to change and improve his behaviour. Somood thought that *"he was growing with no progress"* in his condition (I:p.3) and *"it was not easy to take care of him"* (I:p.4). He needed to be *"enrolled in a private special school to mix with other children"* (I:p.3).

Finding an educational placement

Somood lived outside the main cities, so the options were limited, and she did not *"have many choices"* (I:p.3). It was *"impossible to move to the city"* (I:p.3).

Somood thought of a public special centre, but they *"rejected him, because Tariq was still using a nappy"* and according to them there *"was a shortage in teachers and specialists"* in the centre (I:p.3). She tried to access the integration classes in the MOE, but he was "*rejected from mainstream schools because he still needed to be toilet-trained"* (I:p.2). Tariq stayed *"at home most of the weekdays and had two sessions per week in a private special centre"* (I:p.4). The private special centre provided a *"physiotherapist and a special education teacher"* (I:p.5). Somood explained that she was not involved in the plan the centre set for her son, and that she *"did not follow them up and did not know what they do for him"* (I:p.5). She said that she gave the centre *"total responsibility to teach and develop [her] son"* (I:p.5). Somood felt that a private centre would help her son to *"read and write and would support his understanding of the information given to him"* (I:p.3).

Somood's strategy to support her child's development

At home, Somood felt that she did not have *"any idea how to help him"* (I:p.6), except to take him to a doctor, who checked *"that he was physically fine"* (I:p.3). She thought that the *"specialists, schools, and centres"* would be able *"to reduce his tantrums"* (I:p.2) more than she could.

Somood's perceptions of the services available for children with ASD

Somood thought that *"each child had the right to learn,"* but there *"were no services available for children with ASD in Oman"* (I:p.2). There *"were only private centres, which were expensive"* (I:p.2). The MOSD rejected their *"application for funding [her] son's education"* because her husband had *"a good income*" (I:p.3). The MOE rejected the request to let him in the integration classes (I:p.6), because *"the teachers were not qualified"* (I:p.6).

Somood thought that her limited information was because she *"did not go out"* (I:p.2). Her primary source of information was a *"WhatsApp group."* This group had helped her to increase her *“self-satisfaction and self-conviction of what she had,”* and to *“accept [her] child as he was, and not to feel like the only mother with a child with ASD”* (I:p.6).

Family/community support

Somood expressed feelings of gratitude towards her family because *“everyone in the family (brothers, sisters, and daughters) supported [her], but they were also helpless”* (I:p.6). Her two daughters and her husband *“were taking some responsibilities in taking care of [her] son”* (I:p.4). For example, the husband took *“care of Tariq, changed his nappy, took him out for a walk, or took him to the beach or the park”* (I:p.4).

Hopes and concerns

Somood hoped that one day, her son would *“be a doctor or an engineer,”* or at least *“learn like other children his age”* (I:p.3). She hoped that he would be *“a healthy and ‘normal’ child”* (I:p.7). She was anxious about his *“future, his condition, and about him”* in general (I:p.7).

To sum up, Somood was really disappointed with her son’s condition and felt that she needed help to teach her how to deal with him.

5.3.9 Sondos and her son, Munthir

Sondos is a working mother, and her son, Munthir, was six years old when I met her. Sondos had two children. Munthir attended a private mainstream school.

Purpose of education

Sondos thought that education meant *“reading and writing, doing homework”* and studying *“different subjects*” (I:p.1), while rehabilitation could mean *“early intervention for the first year after diagnosis”* (I:p.1). She defined ‘cure’ as *“using medication and food replacements”* (I:p.1). For her son, Sondos thought that Munthir needed *“integration, in which he gets a place in a mainstream school,* *but he has an individual plan"* (I:p.3) because she thought her son *"had the potential"* to develop and *"education was important for him."* Besides, she thought that *"integrating him in the community would be more important"* for his development (I:p.4).

Finding an educational placement

Based on her definition of the meaning of education and her son's needs, Sondos tried to find a place for him in a private mainstream school. She had to change school twice. She was looking for a school that was able to deal with children with ASD. Sondos emphasized that her *"first impression"* about the school and *"being convinced about staff's ability to work with [her] son*" were the criteria for choosing or rejecting a school (I:p.3). There were other factors in choosing a school for her son, including *"the availability of transportation, realistic fees, and whether the curriculum is designed to meet [her] son's needs"* (I:p.2). Sondos was currently evaluating the school her son attended. Her criteria for choosing a new school were her *"son's development,"* the *"teacher's ability,"* the *"Ministry's new assessment for schools,"* that *"the language used in school should be Arabic," and "the school's acceptance of children with ASD"* (I:p.2). She had changed school the first time because of transportation, and she was considering changing the current school because she did *"not trust"* it, *"its level was not good, and the teachers were not helping to develop [her] son's potential"* (I:p.1). The school was integrating him in a mainstream class, but there was *"no specific or individual plan to match his needs,"* but she had a concern that *"changing school affected him negatively"* (I:p.1). Sondos believed that there were *"no schools that would accept children with ASD"* (I:p.4). If she thought about schools, her choices would depend on the *"quality of teachers working in the school*" (I:p.4).

Sondos' strategy to support her child's development

Munthir was *"very connected to his mum"* (I:p.5). Therefore, Sondos attempted to use this to support his development through *"simplifying the task, using drawing and using repetition"* (I:p.2), because usually he *"does not like doing homework"* (I:p.3). Sondos thought that *"opening the school bag as Munthir gets home*" would *"attract him to do homework."* She also thought that using a *“strict but loving”* strategy helped her to manage his behaviour when doing his homework. In addition to that, it was essential to *“break the tasks into smaller tasks”* so they would be achievable (I:p.3).

Sondos’ feelings

Sondos described her feelings of *“struggle, as [she] faced rejections from many other schools”* (I:p.3). She experienced feelings of *“regret”* and *“blame”* because she felt she was *“the cause of her son’s condition”* (I:p.4). She also had the feeling of *“regret”* towards her choice of the current school, because *“the school vision did not match the school’s work and there was no clear vision”* (I:p.2). However, there were feelings of satisfaction for her, because her *“son had developed greatly, he communicated well with his mum”* (I:p.6). Besides, she felt *“happy”* if he showed development. Sondos felt *“sad each time she looked at him.”* She had a feeling of *“trust in God that he would make things better.”* She would feel successful when her son *“succeeds in his life.”* Sometimes, she felt depressed *“when [her] son was not treated fairly”* by the community (I:p.8). Sondos stated that there was not *“a single teacher who is like Helen Keller’s (the famous first blind-person who earn a Bachelor degree in Art) teacher”* to take care of her son (I:p.9). Sondos tried to *“overcome stress and sadness, by [her] strong faith in God to choose the best for [her] son”* (I:p.5).

Sondos’ perceptions of the services available for children with ASD

Sondos stated that there were *“no services available for children with ASD in Oman,”* and that there were *“no health services, and the doctors were not qualified.”* The MOSD *“allowed private centres to offer services for the citizens but did not supervise them.”* The MOSD *“established rules that made the private centre’s work difficult”* (I:p.7). She felt angry *“when the MOE announced that there was no budget to fund teaching children with ASD”* (I:p.8). She only managed to access some services, such as *“paying the fees for the centre (her) was going to”* (I:p.8).

Family/community support

Sondos thought that the *"community does not accept children with ASD because people were not aware of the meaning of ASD"* (I:p.5). The only support she had from her family was from her *"eldest sister,"* who was supporting her and her decisions (I:p.5). Her *"husband was not supporting his son,"* however, she thought that *her son "needed his father"* (I:p.7).

Hopes and concerns

Sondos hoped that her son would be able to *"to have friends," "to find a school that could accept him,"* and *"to be independent"* (I:p.7), while her main worries were that she would not be able *"to find a place for him to go and he would stay at home"* (I:p.7).

To sum up, Sondos thought that it was important for mothers to *"accept their child's condition"* and *"to start as early as possible"* at helping their children with ASD. She felt that she needed to *"live a 'normal' life, not to be negative and not to lock herself away in worry"* (I:p.6).

5.3.10 Thana and her son, Majed

Majed was a 17-year-old boy who was staying at home at the time of the interview. Thana was a housewife, and Majed was her only child.

Purpose of education

Thana thought education meant *"joining a school, and learning reading and writing"* (I:p.3). But at this age, she felt that Majid needed training to *"be independent,"* because he was an adult, so he needed friends around him. He needed *"football training," "something that suits his age,"* (I:p.6) and did not need *"cutting and pasting"* activities.

Finding an educational placement

Thana tried to find a place for him in Oman by *"visiting some local schools and inquiring at the admissions department in the MOE"* (I:p.3). When he was very young, she *"enrolled him in a mainstream nursery"* (I:p.3). However, Thana narrated how the *"school rejected him"* (I:p.4). Therefore, Thana decided to send her son *“abroad to join a centre for children with special needs in Jordan.”* She thought that he *“benefited, but not that much.”* He *“settled in well”* and *“became more independent.”* Thana was told that *“the teachers in that country were good at dealing with children with ASD”* (I:p.6). Later, she found out that the centre *“was locking them in rooms alone”* (I:p.6), so she brought him back and enrolled him in a special centre for children with special needs in Oman, but he *“did not benefit at all”* from being in this centre (I:p.6). Then she stopped trying to find places for her son, because of *“financial expenses, family problems, and problems with [her] husband”* (I:p.7). She tried to enrol him in *“a public special centre for children with special needs, but [she] never received a reply to [her] application”* (I:p.11).

As her son grew older, she thought of *“hiring a special teacher,”* but according to her, these teachers *“were doing activities that would not help Majed to talk”* (I:p.12). She described how difficult it was *“to find someone to help Majed”* (I:p.11). Even if she managed to find someone, some obstacles stopped her from taking on a teacher, including the problem that the *“timing did not suit [her]”* and *“expensive fees that [she] could not afford”* (I:p.6).

Thana’s strategy to support her child’s development

At home, she tried to help her child through *“reading the Holy Quran, and taking him to traditional healers”* (I:p.1,2). She continuously *“took him to traditional healers, but [she] was not convinced that they could help him”* (I:p.2). Later, she adopted the *“Son-Rise programme to support his development”* and *“used educational toys at home”* (I:p.3). She thought that using the *“TV, an iPad, books, games, and clay would support her child’s development”* (I:p.3, 5). However, she felt that her son was *“not benefiting much, and he did not need these anymore”* (I:p.5), so she enrolled him *“in a gym and used physiotherapy for three months”* (I:p.4).

Thana used methods such as *“talking to him continuously”* and *“teaching him to smile if he was happy”* (I:p.7) in order to help him express himself. She also used strategies such as *“spending time with him before sleep, reading stories for him, taking him to the beach and asking him to help with the housework”*

(I:p.10). She was planning *"to move to a new house, where she could plan new things for [her] son"* (I:p.8).

Thana's perceptions of the services available for children with ASD

Thana thought that there were *"no services for children with ASD in Oman" and "no support for children with ASD"* (I:p.4). She tried to *"access government services, but they were rejected"* (I:p.11). Even if there were very few public special schools, Thana did not *"trust them"* and thought that *"there were no good schools"* (I:p.12).

Family/community support

Thana could not find *"family support from [her] brothers," nor "from [her] husband's brothers."* Even her husband *"was not supporting [her]"* (I:p.8). He was attempting to take some responsibilities, but she felt that he needed to do more.

Hopes and concerns

Thana hoped that Majed would find *"someone to play with, have fun, go out, be independent, spend some time apart from [her], and play football"* (I:p.3).
Thana hoped that she would *"hear Majed's voice recite the Holy Quran,"* and that he would *"learn Karate, learn to play an instrument, ride a horse, learn swimming, have friends, and learn drawing and painting."* She did not think that it was vital for him to *"learn like other typically growing children"* (I:p.7), but she hoped to find *"something that suits his age,"* as he was 17 (I:p.8). Her main concern was that *"something bad would happen to [her] son, as he could not speak and could not defend himself"* (I:p.13).

To sum up, Thana felt that she could not find support for her son in Oman. She therefore advised other mothers of newly diagnosed children with ASD that, if they had enough money*, "it was better to take their child abroad because their child's development would not be in Oman"* (I:p.12). Thana, throughout the interview, showed feelings of helplessness because she *"felt her marriage was* *unfair, and she had to accept destiny”* (I:p.3). However, she expressed feelings of satisfaction *“about [her] son’s development,”* and this *“led [her] to be stronger”* (I:p.12). Currently, Thana said that she was *“waiting for a miracle to help Majed”* (I:p.13).

5.3.11 Zeina and her son, Obaid

Zeina was in the UK when I interviewed her, and her son, Obaid, was ten years old. His current school was a complex needs school in the UK. Zeina has two children in total who lived with her.

Purpose of education

Zeina stated that Obaid’s current school was *“a complex needs school in the UK”* (I:p.1). According to assessments, Obaid had *“sensory needs, did not like noise, bit himself, liked to be with adults, and did not have any academic skills”* (I:p.2). Obaid liked *“to discover things and liked quiet places”* (I:p.13, 14). However, he was *“able to go to the toilet, eat independently, serve himself and find his toys”* (I:p.3). Zeina said that she was looking for an education that would meet his needs and to help him to *“be independent, to understand what is going around him, and to react to what goes on around him.”* Education for Obaid was to *“meet his needs like toilet training, feeding himself, self-defence and understanding danger”* (I:p.3). She thought that people with ASD needed *“lifelong teaching,”* and she had *“to cope with it”* (I:p.3). Obaid did not need *“academic skills.”* His education was different from his sister. Zeina explained that *“his sister learned from everything around her (school, IPad, books, and magazines) and she was independent,”* but Obaid *“needed a trainer to train him, needed repetition to learn”* and *“needed intensive training”* (I:p.3, 11).

Finding an educational placement

Zeina’s definition of education was *“not academic,”* but rather meant training her son *“to be independent” and “meeting Obaid’s needs”* (I:p.4). When Zeina was in Oman, she enrolled him in a nursery in the mornings, which was good because it *“helped [her] in training and developing [her] son’s skills”* (I:p.4). It was good because it had a *“good learning atmosphere”*, *“the size of the class was small”,* the nursery worked to *“meet [her] son’s needs”* and there was *"continuous care during the day"* (I:p.5). However, when he was 7, she had to find another school for him. She wanted him *"to be in an academic environment and to learn reading and writing, because he needed to acquire life skills and be in a safe environment"* (I:p.8). Zeina's criteria for choosing a school were, *"qualified staff, the school's history in dealing with children with special needs, the school's acceptance of children with ASD, acceptance of a mother's involvement in her son's education, cooperation between school and mother, whether the school respected mother's opinion, whether they were able to understand the child's needs,"* and that *"it should be close to [her] house"* (I:p.7). Obaid attended a private special centre in the evenings. Zeina was not satisfied with this, but at least it had *"a learning environment, a speech therapist, an occupational therapist, special education, one-to-one sessions, physical therapy, physiology therapy and a sensory room"* that helped Obaid (I:p.8).

Then Zeina moved to the UK and tried to find a place that would meet Obaid's needs. He started in *"a mainstream school,"* moved to an *"additional support school"* and later moved to a *"complex needs school"* (I:p.1). This *"was done after assessing his needs"* and *"it was the council's decision"* (I:p.1). She described how the decision was taken after a *"meeting with [her], involving [her] in decisions, and assigning a settling day for Obaid and another day for [Zeina] to visit the school"* (I:p.1). They moved Obaid three times because he had *"sensory needs"* and *he got "agitated and aggressive with himself."* Other children in the first two schools were *"verbal and hyperactive"* and *"he could not cope"* (I:p.2). Though it was not Zeina's personal choice, she expressed satisfaction with the new school (I:p.1). The reason was that she could see that they *"were meeting Obaid's needs,"* and she had *"frequent meetings with teachers."* Zeina thought that she did not *"know much about the school because Obaid had moved recently to the school"* (I:p.1). However, she stated that she felt comfortable about the school's strategy with children with ASD as they *"talked to the children about what they were going to do next"* (I:p.1). They also provided transport for her son as her home was far away from school, and according to the council, this was *"the only available school that would meet his needs"* (I:p.2).

Zeina struggled to *“find a school for her son,”* which led her *“to move to another rented house, hire a housemaid,”* and *“to pay money to support [her] son’s development”* (I:p.4). She faced difficulties with the private centre her son was attending in the evenings because it never *“respected [her] involvement in [her] child’s plans, had negative attitudes towards [her] comments,”* and she felt that her *“son’s needs were not met*.” Zeina did not *“trust the centre”* he was in (I:p.7). They were *“unable to understand him, and there was no continuous care for his needs”* (I:p.5). As a working mother, time was a challenge she faced in training her son (I:p.11).

Zeina’s strategy to support her child’s development

Zeina said that her son needed *“patience and repetition”* in order *“to learn life skills”* because he *“took a long time”* (I:p.3). *“Training should be designed and directed to him,”* and he *“needed one-to-one training”* (I:p.4).

Throughout the interview, Zeina described different strategies that she used at home to support Obaid’s development, including *“changing the environment, making eye contact, and being face to face when training him.”* It was important to *“choose a suitable time for training, and not when he is angry, hungry, upset”* (I:p.4). She adapted the *“Son-Rise programme”* [see glossary], which was *“a beneficial experience”* for her and her son (I:p.5). She used *“water, clay, sand, and playdough”* as comforting teaching strategies for her son, and she had prepared *“a sensory room using music, flashing lights, and rhymes”* to develop *“his motor-skills”* (I:p.5). She used strategies such as *“cuddling, smiling, being patient, repetition, not quitting, and persisting.”* Zeina thought that effective strategies for her son should be *“fun”* and *“practical”* (I:p.10).

She used to *“give him a choice, allow him to try first and give him space to choose what to do,”* but she *“would be there if he needed support”* (I:p.14). Zeina thought that taking *“him to different places”* did help Obaid’s development, but she needed to take *“something to comfort him, like his playing pipes”* (I:p.15).

Zeina thought that she *“had experience*”; she gained her experience from *“reading, learning, trying things, attending workshops, and training other mothers*.” She thought that she knew what *“was good for [her] son.”* She usually kept her knowledge up to date (I:p.11).

Zeina’s perceptions of the services available for children with ASD

Zeina thought that there were not enough services for children with ASD in Oman. There were *“no private centres for people with ASD, nor public centres”* (I:p.15). She thought that *“the diagnosis service was good, but it was done only once”* (I:p.16). The MOSD *“funded children with ASD, but once they grew older, there was no funding for them”* (I:p.16).

Zeina explained that *“the country was behind other countries in the field of ASD and had a low level of education for children with ASD. All the services were for preschoolers”* (I:p.15). She knew that there were *“integration classes in the MOE, but there were difficult criteria to get a place for a child in these classes”* (I:p.15). Zeina thought if she could *“afford to live abroad,”* she would continue living in the UK and would not go back to Oman, because the UK *“had lifelong services for children with ASD”* (I:p.16).

Family/community support

According to Zeina, the Omani community *“was not aware of ASD.”* Their *“negative comments”* made her feel that she was *“doing nothing,”* and that she *“was not doing [her] job towards [her] son and always comparing Obaid to others”* (I:p.16).

Hopes and concerns

She thought that Obaid’s development was *“slow, but there was progress”* (I:p.12). Her main worry was that *“Obaid had not learned about privacy yet*” and she was worried about him *“running away from home”* and never being able to come back home (I:p.13). In general, Zeina had feelings of being *“confused, not sure, and not optimistic about the future”* (I:p.6).

To sum up, Zeina's advice for other mothers with newly diagnosed children with ASD was to *"focus on training, to be patient, break tasks into smaller manageable steps, show them how to do things, teach them and give them a chance, use simple language, be persistent, use repetition, and trust the child"* (I:p.11, 12).

5.4 Findings from Phase 3 (building-rapport days)

This section presents a summary of the three building-rapport days which were carried out in order for me, as researcher, to be part of the real-life setting with a mother and her child with ASD. Fatin, Shojoon and Zeina were the mothers who accepted my participation in a building-rapport day. Through analysis of the data collected on these days, three main themes were identified as explained and described in methodology, Chapter 4 (see section 4.8). These are: the nature of the mothers' lives with children with ASD; family support; and the mothers' strategies to support their children with ASD. Table 5.1 presents a brief description of what occurred during the building-rapport days.

Mother's Name	**Time**	**Place and Activity**	**Mother's explanation of the reason for the activity**	**Who was involved?**
Fatin	4 pm- 5pm	Pin activity (children were using plastic pins to draw shapes such as circles, squares)	-To increase the children's concentration, vocabulary. -Teach shapes -For fun	-One son with ASD (Hassan) -Daughter typically developing -Two children with ASD (5-6 years old) -One girl with Down Syndrome.
	5 pm-6pm	Drawing activity (children drew a cow)	-To increase their vocabulary -Fun	
	6 pm-7pm	Playing activity (children) + One-to-one Speech Activity (Fatin spent 15-20 minutes with one child)	-To increase their vocabulary -Fun	
Shojoon	8pm	I arrived and Shojoon welcomed me in her home	-	-The housemaid -two daughters with ASD (Hoor and Noor) + son (Khalil)
	8 pm- 7am	Sleeping time We sat together to plan the next day	-	

	6.30 am-7.00 am	Shojoon prepared her children for school with the assistance of the housemaid	-	The housemaid and three children
	7.30 am-1.30 pm	-Children at school -Shojoon at work - I went out	-	-
	1.30pm-3.30pm	- All return and in one room - Shojoon talked to me about her children and some of the strategies to keep them safe - The three children were eating and watching TV	So children can spend time with each other	-The three children - The housemaid frequently joined us in the room to check if Shojoon needed any help
	3.30pm-5.00 pm	Outside the house in the house yard Children were playing in the play area and playing games. Shojoon and I were chatting and watching them	To play To have fun	-The three children - The housemaid frequently joined us in the room to check if Shojoon needed any help
	5.00 pm-8.00 pm	We went to the Park, children were playing in the play area	To play To have fun being outside the house	The three children
	8.00 pm	I left		
Zeina (Lived in UK)	Thursday 4.00 pm	I arrived and Zeina welcomed me	-	Obaid (Zeina's son) Areej (Zeina's daughter)
	4.00pm-5.00pm	Lunch	-	Obaid Areej
	5.00pm-8.00 pm	Zeina talked to me and described things that she was doing to help her son, such as the way she supported his eating, getting dressed etc. Children were watching movie.	To be independent	Obaid Areej
	8.00 pm – 7.30 am	Sleeping time	-	-
	Friday 7.30 am- 9.00 am	Zeina prepared her children for school. I was there when she was helping the children	- to support his independence	Areej Obaid
	9.00 am-4.00 pm	Children were in school Zeina and I stayed all day at home talking about our children with ASD (Sharing experience, concerns,)		
	4.00 pm	Children collected from after school club.		
	4.00 pm-6.00 pm	Restaurant for meal	-	Obaid Areej
	6.00 pm – 7.00 pm	Park	To have fun and play in the play area	Obaid Areej

	7.00 pm - 8.00pm	Sleeping time	-	-
	Saturday 9.00 am	Breakfast time	-	-
	9.00am-12.00pm	Preparing myself to leave		
	12.00 pm	I left		

Table 5.1: Description of building-rapport days

5.4.1 Building-rapport day with Fatin

The day in **Fatin**’s house was not a full day because she asked me to join her in a three-hour session where she was teaching other children with ASD, along with children who were typically developing. Fatin has two sons with ASD. The elder one (Khozam, 9) was living in a school outside Oman, and she was taking care of the younger son (Hassan, 4) at home. There were five children in her home: her son and two other children with ASD, one girl with Down’s Syndrome and Fatin’s neurotypical daughter. She was trying to support her son as well as other children. Fatin explained that she had a degree in Special Education Needs and she said she was able to support each child’s development. The main finding identified from this data was about strategies to support her son’s development (and that of other children with ASD). Because the time was short (three hours) it was difficult to observe the nature of Fatin’s life as a mother, although she did seem to take a particular approach to this role in having other children to the house to ‘teach’. Fatin varied in using group and one to one activities, purposeful play, and socialising activities. During this session, Fatin said that these activities were an attempt to support her son in socialising with other children through playing and sharing activities (see table 5.1). She used play by asking children to produce and paint drawings and to play games. She also took one child at a time to help him/ her to develop his/her speech. She was using words such as ‘cow’ and ‘big cow’, focussing on pronunciation. When Fatin was working one-to-one, the other children were playing with each other using the toys and games in the room. The children were quiet and followed Fatin’s instructions most of the time, except one child with ASD who jumped and screamed which disturbed the other children during the three hours. Fatin’s typically developing daughter supported other children by playing games with them, such as ball games and board games, when Fatin was working with this boy. At the same time, Fatin was using a speech activity with one child when they were playing. All children were collected by their mothers at 7pm. Fatin explained that this was the end of her teaching session for the children in her house, and I left at this point.

5.4.2 Building-rapport day with Shojoon

The day with **Shojoon** was longer, as I visited her home for 24 hours and slept there. Shojoon was taking care of her two daughters with ASD (Hoor 9 and Noor 4) and one neurotypical son (Khalil) by herself throughout the whole day; she also involved and trained the housemaid in taking care of them. The importance to Shojoon of keeping the children safe was a major finding from this building-rapport day. We stayed home most of the day, except in the morning, and went out to the park for one hour at the end of the day. I noted that she organized the house in a way that was safe for the children, so they did not hurt themselves. For example, she made sure she locked the outside door of the house, so they could not wander out if she was busy and she did not keep keys in any doors so they could not lock themselves in a room or a toilet. In addition, Shojoon seemed to identify and respond to her daughters' needs; for example, on one occasion she noticed that her eldest daughter was upset and so she tried to attract her attention to something else. Shojoon told me that she sometimes did not respond to her youngest daughter's (Noor) tantrums when we were at the park, as a strategy to help both her children with ASD. I noticed that Shojoon was also taking care and looking after the daughters and preparing them for school, taking them to toilet and taking them to bed.

5.4.3 Building-rapport day with Zeina

I spent around 36 hours with **Zeina** and her two children, Obaid and Areej. Obaid was her son with ASD, aged 8, and Areej, her daughter, aged 10. I was focused from 4pm Thursday to 4pm Friday, but there were a further 12 hours before I left the house. We spent most of the time at home, but we went out to the park for one hour and we also went out for lunch. Being in different settings showed me how Zeina supported her son and the nature of her life with a child with ASD. From the analysis of the data of the time I spent with Zeina and her children, three things were apparent: she was continuously thinking about and taking care of her son; her daughter supported her in taking care of her brother; and Zeina implemented a range of strategies to support her son's development. In terms of thinking about and taking care of Obaid, one example is that Zeina prepared a small corner of the living room with his favourite toys as a comfort zone and if Obaid got upset for any reason, she would take him there. In addition, she always took a comfort toy with her when she went out to support Obaid if he had tantrums. Sometimes, Obaid showed signs that he needed the toilet and Zeina would then take him to the toilet, for example, in the restaurant. This shows that she was continuously thinking about Obaid's needs, and when he cried, she knew what he wanted. Her daughter's support was observed in a number of ways. For example, I noticed that when she watched movies with her brother, she explained events in the movie to him. She also helped her mother when preparing him for school. Though Zeina would ask her daughter to look after Obaid, she would jump in and check that he was fine and that there was nothing dangerous around him. Zeina also showed some strategies which she used to develop her son's independence, such as allocating a plate for him in the kitchen so that he would eat by himself. She also enrolled him in an after-school club and, in this way, helped him to socialize with neurotypical children.

Overall, the three building-rapport days served to provide real-life settings to observe the lives of mothers of children with ASD and see how mothers 'deal' with their children on a daily basis. These days highlighted the nature of the mothers' lives with children with ASD; family support; and the mothers' strategies to help their children with ASD. Life as the mother of a child with ASD seemed to require continuous attention to care for them, and to require constant thinking of new strategies in order to meet their needs. It also seemed to require the mother in involving other family members, such as siblings (Fatin and Zeina) or a housemaid (Shojoon), to assist her in taking care of her children.

5.5 Cross-case analysis

The previous sections presented findings in the form of summaries of the mothers' stories from Phases 1, 2 and 3, while this section presents a cross-case thematic analysis of the data obtained from all three phases (25 story narrations (S), 11 interviews (I), and three building-rapport days (BR). Themes for all phases were identified through the process of analysis described in the methodology (Chapter 4). These themes are presented separately here, with convergences and divergences highlighted to demonstrate the breadth and depth of each theme (Smith, 2011). There are, however, interrelationships between them. To illustrate the themes, examples of translated verbatim quotes from interviews, story narrations and building-rapport days are included. The inclusion of quotes from mothers is intended to highlight mothers' thoughts about their experiences. In order to support the presentation of data, tables are used in the discussion of some themes to provide a summary of relevant data or contextual information, so (S) stands for story narrations, (I) stands for interviews, and (BR) for building-rapport days.

5.5.1 Early signs and diagnostic struggles

In both their stories and in their interviews, the 25 mothers identified **concerns about their child's development** between the ages of one month and three years. Despite their concerns, a diagnosis of ASD was not generally confirmed until after making frequent visits to the GP and local hospital. Three mothers did not have a precise diagnosis of their child's condition. For example, Njood did not know that her son's condition was called ASD until he was almost seven years old, when she attended a workshop about ASD in her town. *"We did not have a precise diagnosis; after that, we knew that he was a child with ASD"* (Njood, S).

Four of the 25 mothers thought that their children were growing typically until the age of 18 months, when they noticed changes in their children's behaviour. They explained that they noticed a change or a switch from being 'normal' to 'different.' Anfal felt that her son started to *"lose the words he was uttering and showing isolation."* He would be *"sudden[ly] crying and laughing for no reason,"* and he had *a "lack of sleep."* Mayada (S) said that her son *"stopped talking,* *forgot the words Mama and Papa, did not have eye contact, and he was always daydreaming."* Razan (S) also described changes when *"ASD symptoms started to appear"* in her daughter at two years and two months of age. She was *"laughing and crying without reason. She was scared without reason, sometimes was scared of walls, afraid of red lights, she isolated herself and had sleep problems."* The 25 mothers described similar behaviours that led to concerns about their children's 'normality'. They repeatedly mentioned in their stories that they suspected that their children had *"hearing problem."* Most of these behaviours were common across many of the children in this study and can be summarised as sleep problems, hyperactivity or being inactive, changes in behaviour and understanding, avoiding eye contact, screaming for no reason, fear of loud voices, and problems in communication and speech. Some mothers also explained that they noticed that their children were different from their older siblings. Five mothers described how their children were initially 'normal', and then they changed; in particular, they noted that their children stopped talking. Aseel wrote, "*We noticed that he forgot the words he used to say*" (Aseel, S). The other 20 mothers did not mention that their children were 'normal'; instead, they did mention that their children had a speech delay or they were *"only babbling without any speech"* (Athari, S) or *"uttering incomprehensible sounds"* (Fatin, S).

13 mothers tried to investigate their children's condition in Oman, either in a private hospital or a large public hospital. Seven other mothers tried to find out about their children's condition outside Oman; this was either because they were not convinced about the diagnosis carried out in Oman (Fatin, Shojoon, Mayada, and Shahad), or because they were studying outside Oman (Athari and Zeina). Fatin took her *"son abroad for diagnosis"* (Fatin, I:p.6). *"The doctors in Thailand diagnosed [Shahad's son] with ASD,"* while in Oman, *"doctors were not clear about his condition"* (Shahad, I:p.4). Five mothers did not mention anything about the location where they received their children's diagnosis; two of these did not want to seek a diagnosis. One such example, was Samaher, who *"never had [my daughter] diagnosed or took her to a specialist"* (Samaher, S).

Mothers' **initial responses** to the diagnosis of their children with ASD varied from one individual to another. They displayed feelings of shock, depression, fear, sadness, surprise, denial, and the desire to cry, and felt confused about what was meant by ASD. Mariya, Rafif, Shahad and Zulfa wrote that they had refused to accept that their child had ASD. Some mothers reported their feelings towards their child's diagnosis as being strong, such as Ibtihal, who described it as *"a shock for [me]"* (Ibtihal, S). Jumana thought that the diagnosis created *"a strong responsibility"* towards her son, along with *"a great desire to make him overcome this disability."*

In 11 of the story narrations, the mothers' perceived **reasons for their children's conditions** were given**,** such as physical or health-related problems, environmental triggers, or hereditary reasons based on superstition. Aseel stated that the cause of her son's condition was a vaccination. ASD in *"most of the children was caused by vaccination,"* she believed, and her *"son is one of them"* (Aseel, I:8). Maha thought that her son's condition was due to problems related to pregnancy and birth, as *"he had many problems in pregnancy, including high temperature, and he was not breathing when he was born; he was suffocating"* (Maha, S). Others believed their children had physical health issues; for example, Fatin's son, Khozam, was medically diagnosed as having *"a deficit in the left lobe of his brain"* (Fatin, S). Mayada felt that the cause was more related to the medicine given to her son in the early days after he was born. *"He had drowsiness in the thyroid gland."* She stated in her story that "*this cause was confirmed by the doctors who diagnosed her son with ASD*"; they told her that the cause was the amount of *"medicine used to cure his thyroid gland"* (Mayada, S). Zeina thought that because her son had health problems at a very early age, he continued to "*receive many types of medicines and antibiotics throughout his first 24 months*" (Zeina, S), which might have caused his condition. Mariya felt the reason was environmental, as *"she left him a long time in front of the television"* (Mariya, S), while Razan felt that her daughter was fine until *"something happened to her at a cousin's party."* She tried to relate it to jealousy, or an evil spirit that had affected her daughter. Thana also mentioned the cause for her son's condition in her story, stating that *"it was an evil spirit, and maybe my child was affected by it."* However, Thana also believed that the cause of her son's condition was hereditary, as her husband *"was suffering from epilepsy"* and *"if he had a baby, to some extent his children would inherit this"* (Thana, S).

The mothers' stories illustrated how they attempted to interpret the causes of their children's conditions and never having experienced ASD before. There were indicators noticed by the mothers that their children were not typically developing, which made them seek out and try to interpret the possible causes for their conditions.

Not understanding the child's ASD diagnosis was a common topic in all mothers' story narrations and interviews. Mothers seemed to remain uncertain in the early stages in terms of accepting and understanding the diagnosis and what it meant for their children. Some stated that they had never heard of the term ASD before receiving a diagnosis for their child and had confusion about the meaning of ASD. Almost all the mothers in the story narrations, 24 of the 25, added that the confirmation of a child's condition as being ASD was a catalyst for them to change their children's behaviours, find treatment and seek out more information through reading and other research. *"ASD was a new term I had never heard of, so I began to search and look for its meaning, symptoms and the methods of treatment"* (Rahaf, S). Sondos and Ibtihal described their feelings about the diagnosis of ASD for their child:

> *"I spent my days reading about autism, and I was disappointed because what I read made me worry about my child and his condition. Many questions came to my mind, but unfortunately, I could not find any appropriate answers for them. I ended up at the conclusion that autism is a dark world"* (Sondos, S).

> *"I wondered what this was. Was this a disease and was there medicine for it? Would he be cured, how would I treat him, and where would I go with him? I was not sure what the doctor said. So, I went to another centre, and they told me the same thing. I did not understand it and it was a shock for me. I did not understand what they meant by ASD."* (Ibtihal, S).

They were left with many unanswered questions and were left guessing about what would happen to their children. Mothers were not given guidelines on how to deal with their children or where to take them upon diagnosis.

A few mothers also expressed regret about not attempting to understand the condition better. Athari, for example, *"regret[s] his early stage,"* as she could have done something different to support her son's development. She stated that if she *"had understood his condition"* as being that of ASD, then she would have attempted to deal with it in a different way. She thought that his condition was *"only related to his speech,"* which might be overcome with speech sessions. She thought that there might be other things that might help him, such as *"special schools, so [she] could have talked to them."* And she felt the sessions given by the government hospital were not enough, *"which was one session per week."* Her regret was highlighted when she said that, *"if [she] had known what [she] know[s] now, [she] would have doubled the sessions he had and would have dedicated more time for him"* (Athari, I:p.6).

In sum, the themes in the early stages and the struggle for a diagnosis encompass other subordinate ideas, for example related to mothers' concerns about their children's development. Behavioural changes were identified at an early age by the mothers, and these led them to question their children's development, as well as their experiences towards the diagnosis of ASD. Mothers also reported their attempts to identify the reasons for this condition, and the struggle they faced in order to get the diagnosis for their children, be it inside or outside Oman.

5.5.2 Finding 'solutions' for their children's conditions

Many mothers' stories in Phases 1and 2 mentioned a search for treatment or therapy that could help their children with their condition before they focussed on finding an educational placement. This could be interpreted, from a medical lens (see chapter 3), to mean that they felt it was essential to find treatment first, and then think about educational placement later. It could also depend on the age of the child, so mothers of children of an early age were keen to find a treatment, unlike mothers of older children who were keen to find a placement for them. This commitment to searching for solutions or possibilities that could help their children was common across all cases and all data collection phases.

Mothers' stories portrayed a great sense of urgency and purpose in **seeking solutions** for their children's condition. Some mothers reported that they were hoping to find a 'cure'. This urge or need pushed some mothers to explore unconventional or controversial interventions, and their stories shed light on the many strategies and interventions that they located or were advised about by doctors or relatives. The therapies that the mothers stated they used are displayed in Table (5.2), which summarizes these therapies and shows the varieties which the mothers attempted in order to find a 'cure' for their children's condition.

Therapy/treatment mothers stated that they used with their children	**Number of mothers** **(n = 25)**
Diet therapy (e.g., gluten-free diets, casein-free diets, and supplements including vitamins)	8
Speech therapy	7
[1]The Holy Quran and traditional healers	6
Functional therapy	3
Occupational training	3
Use of medicine	2
Physical therapy	2
Unspecified therapy programmes	2
Electricity therapy	1
Chinese therapy using acupuncture needles	1
Hyperbaric oxygen sessions	1
Rehabilitation	1
Behaviour therapy	1
Son-Rise programme	1
Behavioural therapy and physiotherapy	1
Audio integration	1
Educational plan	1

---

[1] Muslims believe that the Holy Quran is a therapy for all types of illnesses.

Table 5.2: Therapies mothers stated that they tried with their children with ASD.

Mothers reported how they utilized one or more of these strategies mentioned in the table above. A good example showing this was Fatin's story:

> *"We began sessions of electricity therapy and medication to ease the nervousness, but unfortunately, this treatment made the child's condition worse. This seemed to make his condition worse and appeared to increase hyperactivity, distraction, and poor attention. We followed a course of dietary therapy with vitamins and nutritional supplements. Then we followed a course of oxygen sessions and audio integration for 40 days"* (Fatin, S).

For some mothers, these therapies were expensive; for example, the *"diet therapy",* which involved preventing the child from *"eating regular food and giving him special food"* and the *"food and medicine were costly. The quantity of food was little, and its consumption was fast"* (Maha, S).

5.5.3 Finding an educational placement for their children with ASD

After trying some of the aforementioned solutions/therapies, all 25 of the mothers stated that they decided to enrol their children with ASD in **a centre or school** as a way to support their children's development. According to mothers, the centre or school had specialists who would be able to support their children. Eight mothers started with mainstream nurseries, as they thought their children would cope in these nurseries with other neurotypical children, which would help their children's social development. However, some struggled to get them to accept school. One example is Nirmin, who described her son as *"running around most of the time,"* and *"screaming and distracting other children"* (Nirmin, S).

Eleven of the mothers of older children tried to enrol them in a private special centre for children with ASD, while eight preferred public or private mainstream schools for integration purposes. They seemed to think that if their children were integrated with neurotypical children, this would help them to develop socially, and hopefully, academically. Four mothers sent their children to other countries (Jordan, the UAE, Egypt, UK) due to a perceived lack of available services in Oman for children with ASD. Some mothers said that their children stayed at home because they did not have the financial resources to enrol them in schools or centres. Table (5.3) presents information about the types of school that the children of the mothers in Phase1 attended (I focused here on Phase 1 because it includes all 25 mothers and 28 children).

Type of school/centre attended (during the data collection time)	**Child's characteristics** **Verbal/non-verbal**	**Number of children** **(n = 28)**[2]
Mainstream nurseries	verbal	8
Public mainstream school	Verbal	3
Private mainstream school	Verbal	5
Private mainstream school with additional resources for children with special needs	Verbal	1
Home-training	Non-verbal	2
Public special centre	Non-verbal	4
Private special centre	Non-verbal	11
Abroad (UK and Egypt)	Non-verbal	2

Table 5.3: Type of school or centre attended by the children in this study (the total comes to 36 because some children attended more than one place).

Most of the 25 mothers in this study enrolled their children in **a public or private special centre in Oman,** as shown in Table (5.3), where their children would have speech and occupational therapy and special education sessions, as the mothers stated. Fadwa said that she *"always look[s] for a centre that provides speech therapy, swimming, counselling, occupational therapy, physiotherapy to support [her son's] development"* (Fadwa, I:p.2). Even if the children attended mainstream schools in the morning, the mothers stated that they had

---

[2] The number of mothers was 25. Three mothers had 2 children with ASD, so the total number of children is 28

evening sessions in special centres, such as Athari's son, who *"goes to a mainstream school in the morning and has evening sessions in the evening"* (Athari, I:p.3).

Nine mothers (Anfal, Athari, Ibtihal, Jumana, Maha, Rafif, Samaher, Sondos, Zulfa) chose a **public or private mainstream school** because they were looking for integration with neurotypical children for their children. For example, Jumana stated in her story (Phase 1) that she *"decided to enrol him in a mainstream school and integrate him with his peers" (S).* Eight of these mothers stated that they struggled to enrol their children in a mainstream school. For example, Ibtihal's son *"was moved to a public mainstream school, after a struggle with the MOE"* (Ibtihal, S).

Samaher, Rafif and Thana were the only mothers whose children stayed **at home** and did not receive educational provision elsewhere. Samaher had two children with ASD; the eldest attended mainstream school while the youngest stayed at home. It was Samaher's choice to keep her younger daughter at home because she felt that *"her condition was getting worse"* in the special centre. Thana had tried special centres both in Oman and outside the country. When this study was carried out, her son was 17 years old. At that age, there were no schools or centres that would accept him, and she stated that she did not have sufficient finances to enrol him in a private centre, as they were too expensive. She even tried to *"hire a private teacher,"* but again, the private teachers were so *"expensive that [she] couldn't afford"* it (Thana, I:p.11). Rafif's son *"was not enrolled in any rehabilitation centres; he was trained at home,"* and she preferred to teach him at home in the first instance. When she felt he was ready for school, she enrolled him in a mainstream school. She thought that because of *"[her] efforts and support,"* her *"child started to study in mainstream schools"* (Rafif, S).

12 mothers reported that they experienced **rejection from schools** or public services in relation to their children with ASD. Some mothers felt that the reason for rejection from some schools and centres, both public and private, was because of their children's condition. Anfal thought that this was because the schools and centres considered that, *"children with ASD do not have the right*

to be educated in schools." Another reason was their *"limited abilities in education, and the curriculum [that] does not fit their abilities"* (Anfal, S). Ibtihal thought that the reasons for rejection were more related to the schools' readiness to teach children with ASD: "*The public mainstream schools are not prepared for educating people with ASD"* (Ibtihal, S). One example of the schools' readiness, or lack thereof, was uncovered by Samaher when she enrolled her son in a mainstream school. She *"faced problems with the school teachers as they did not accept him,"* but also with *"the students [who] were bullying him"* (Samaher, S).

After experiencing rejection from schools, Ibtihal and Zulfa realised that they did not need to tell the school about their children's condition. Zulfa *"told the school that [her] son had a speech problem, but [she] never told them that he was a child with ASD"* (Zulfa, S). Ibtihal did the same as Zulfa, stating that she *"did not say anything about ASD,"* rather she just told them *"that [her] son had a speech delay"* (Ibtihal, S). This strategy seemed to work for them, and they managed to get a place for their children in a private mainstream school.

Seven mothers, at the start of the process of choosing a suitable place for their children's education, searched **outside Oman**. Shahad and Shojoon sent their children to a special centre in the UAE, which, from their point of view, was their preferred option. Shahad moved with her family to the UAE because for her, it was *"the best choice [that] Mojahid joined a special centre for treatment and rehabilitation for children with ASD"* (Shahad,I:p.1). Athari and Zeina had the chance to travel to the UK for their own higher education and therefore found schools for their children in the UK. Athari had to return to Oman when she finished her studies, though she *"was so much more satisfied in the UK"* (Athari, I:p.6). Zeina still had at least four years left in the UK with her family. Zeina chose to go abroad in order to find a better option for her son. She planned to stay in the UK for four years so that her son would benefit from the services available there for children with ASD.

Thana's son was 17 years old when I met her. She had sent him to a special residential centre for children with ASD in Jordan when he was six years old, and he stayed there for three years. Thana stated that *"[a relative] told [her] that they went to Jordon to teach their son and he progressed a lot in that country, so [she] decided to take him there*" (Thana, S). Thana had also *"been told that Jordan had good teachers and specialists for children with ASD"* (Thana, S). Later, she discovered that the centre was not taking good care of him, so she decided to bring him back.

Fatin travelled to different countries to seek treatment for her oldest son (she had two sons diagnosed with ASD). She stated that she *"took [her] son to Egypt and enrolled him in a private mainstream school with a shadow teacher"* (Fatin, I:p.9) who gave him one-to-one support, while her youngest son was with her and was going to a mainstream nursery in Oman.

Mothers varied in their perceptions and feelings about the centre or the school their child was attending at the time of the study. Some of them expressed **negative feelings** about the school, whereas others felt happy and satisfied. Athari expressed the view that there was a need to follow up the teachers' work with her sons. One reason for this was, she stated, that they were not *"the best teachers that my son could ever have, but at least they [were] better than others."* This feeling about the teachers made her want to *"follow them up"* and give them instruction on the ways *"to train him on what he needs."* Athari thought that she was the one who knew what was her son's needs were, because she *"live[s] with him, and spend[s] more time with him"* than the teachers (Athari, I:p.7).

Ibtihal, Narjes and Sondos also voiced feelings of dissatisfaction about the centres and the ways they taught their children. Ibtihal *"felt very sad and disappointed"* with the way that the teachers were treating her son (Ibtihal, S), while Narjes tried different centres and stated that she was not happy with her *"son's development".* She said that they did not involve her in setting a plan for him (Narjes, I:p.6). Another example of dissatisfaction was reported by Sondos who thought that *"the school vision does not match their work. There is no clear vision"* (Sondos, I:p.2).

Other mothers, however, expressed **positive perceptions and feelings** about the schools or centres chosen for their children. Zeina presented two different feelings, as she was not happy about the centre in Oman, but those feelings changed when she moved to the UK, where she said that she “*feel[s] comfortable because [she] got support from the schools, the teachers and council. [she felt] comfortable because the council decided to support [her] as a mother”* (Zeina, I:p.2).

Shahad and Shojoon considered the private centres to be doing their job in supporting their children’s development. The specialists *“[were] doing their best to help him”* (Shahad, I:p.2). They were *“very supportive, working hard with him. The specialists send videos to me to follow up on his development”* (Shahad, I:p.9). Shojoon stated that *“the centre’s job [was] excellent with [my] two daughters”* and that she *“never regret[s] moving [my] daughter, because Hoor needed more things than what the previous centre was offering”* (Shojoon, I:p.3).

There were many influences on mothers’ decisions around educational placements. The choice between a mainstream school and special centre, in particular, mothers suggested, was influenced by their children’s characteristics. They made suggestions based on their **children’s characteristics**, for example, whether they were able to speak or not, or had other behaviour problems. Table 5.3 shows that some of the verbal children attended a mainstream school, either with or without additional support, while non-verbal children attended special centres. The mothers’ choices between a centre or a school were not apparent in the story narration phase; this was directly asked about in the interview phase when asking about the education provision for children with ASD. For example, Aseel felt that the special centre was the right choice because her son was *“not able to speak or understand”* (Aseel, I:p.1). Shahad also mentioned that she did not even consider a mainstream school because her son was not verbal.

The mothers’ choice between a school or a centre also appeared to be affected by their perception of their child’s needs and what could be provided for them to support their development. Aseel, for example, felt that a special centre was the right choice for her son because *“his education should include teaching him how to depend on himself in life skills”* (Aseel, I:p.1). In comparison, she felt that a mainstream school would not accept *“a hyperactive child who is still in nappies and needs continuous support”* (Aseel, I:p.2).

Frequently mentioned influences regarding mothers’ choice of a special centre were that it *“would meet a child’s needs”* to develop *“life skills”* (Fatin, I:p.3), such as eating, going to the toilet and getting dressed. It was stated by Fatin, Shahad, Shojoon, Somood, and Fadwa, that their children’s education was more related to, for example, “*meeting [their children’s] needs, to develop their understanding of what is going on around them and to be independent in life skills”* (Shojoon, I:p.1).

It appeared that those mothers seemed to think that they were aware of their children’s needs, and, as a consequence, their choice between a school or a centre was related to their understanding of which placement would be suitable for their children. A centre was considered to be a better option because centres usually have *“different specialists, such as speech therapists and behaviour therapists”* (Somood, I: 1). On the other hand, Shojoon argued that schools “*are not suitable for Hoor, nor [do I] think that the teachers are capable of dealing properly with [her] children. In addition, government schools are not qualified to accept children with ASD”* (Shojoon, S).

Zeina thought that her son’s education should be designed for and aimed at him because of his characteristics, where *“Obaid has sensory needs. He does not like noise, and he gets agitated and becomes aggressive with himself”* (Zeina, I: p.). Zeina tried mainstream schools in Oman and the UK, but she found that in UK the mainstream schools “*did not meet my son’s needs*” (Zeina, I: p.2).

Athari chose a mainstream school for her son, but she also expressed the view that her main focus was to develop his social skills. She was *“not bothered about his academic skills. It [was] important for [her] to develop his social and verbal skills”* (Athari, I:p.5). She appeared to believe that her son needed *"integration*" in order to develop his *"concentration and understanding"* (Athari, I:p.2).

Sondos, however, expressed the view that she was more interested in developing her son's academic skills, enrolling him in a mainstream school for that purpose. This is because she found that her *"son has academic skills, and he can read, and he has potential" (*Sondos, I:p.1). Her son's potential encouraged her to find a school for him rather than a special centre for children with ASD.

11 mothers shared **strategies they used to find a preferred placement for their children with ASD**. Their decisions about their children's placements were informed by different activities. These activities are summarized in Table 5.4:

Activities carried out by mothers through their search for a preferred placement	**Mothers** (n = 11/25)
Gathering information (from relatives, other mothers, or the MOE/MOSD)	Athari, Narjes, Sondos, Thana, Zulfa
Moving from their hometown to find better options	Narjes, Razan, Shahad, Zeina
Visiting schools/ centres	Athari, Fadwa, Ibtihal, Maha, Narjes, Shahad, Zeina, Zulfa
Involving the child in the day visit to the school/centre	Athari, Shahad
Meeting and challenging professionals' ideas about inclusion for children with ASD	Athari, Fadwa
Attending workshops in the preferred school	Narjes

Table 5.4: Examples of mothers' activities carried out to search for their preferred placement.

As the table shows, some mothers talked about gathering information from different sources in order to inform their decisions. These information gathering activities included, visiting schools, speaking to others, and speaking to professionals. Athari talked about the activities she had undertaken when thinking about a placement for her son. These included visiting schools and asking about the *“programmes they have for children like Mostafa.”* (Athari, I:p.5). Athari believed that she could *“understand whether they [were] going to integrate him or not from their way of talking about integration”* because she *“can understand if they believe that these children can be integrated or not.”* In addition to that, she spent *“full days with the school, in order to see their performance”* and she also took her son to *“spend a full day with them. In this way, [I could] see”* and could *“observe their way of dealing with him”* (Athari, I:p.5). Athari suggested that these activities informed her choice of the school that would meet her son’s needs.

Another example was Fadwa, who talked about the activities she used to choose a centre, especially as she had changed the centre four times in eight years. Like Athari, Fadwa also played an active role in her choice through *“visiting the centres (three times) and talking to specialists.”* It was essential for her to *“to feel comfortable about the centre”* and to make sure that the *“specialists have similar ideas about [her] son.”* She also mentioned that she *“discussed with the specialists what [her] son needs”* (Fadwa, I:p.3).

Narjes followed similar strategies, preparing an intensive plan for her son every year. Her *“choice depended on recommendations from other mothers.”* Her choice of specialist depended on her *“trust for the specialists, their qualifications, and their willingness to come to [her] home”* (Narjes, I:p.3,4). She *“attended a workshop in a new centre and in that workshop, they talked about toilet-training children with ASD. This encouraged me to enrol my son in this centre. I also heard many mothers recommended it”* (Narjes, I:p.6).

Zeina also employed some of these activities in the UK in order to find a school for her son. She talked about the activities she was involved in in order to find a placement for him, which including visiting schools, having meetings with the school teachers, and spending a day in the school. Although *“it was not totally [her] choice,”* as “*it was the council’s decision,”* she appeared to be satisfied with the outcome*. She clearly stated that she was “satisfied because [she] did not have to make this decision, and later on, regret it”* (Zeina, I:p.2).

Mothers' feelings about their educational placement decisions for their child with ASD were a mixture of regret and satisfaction. Sometimes, decisions seemed to be influenced by the availabilities of services in Oman. The reason for mothers stating that they felt satisfaction about their decisions was because, as Aseel expresses it, they *"had done what [they] could do"* for their children (Aseel, I:p.2). Zeina reported a similar feeling of satisfaction. She gave some examples of the activities she had carried out for her son, arranging for *"all the necessary tests (MRI, CT scan) to check that he is physically fine."* She also reported that she would seek out all options to support her son and she did her *"best as a mother living alone."* She *"paid for the Son-Rise programme,"* saying that *"Anything [she] can do, [she] will do it even if it is challenging for [her]"* (Zeina, I:p.6).

Fatin, Shojoon, Shahad and Thana expressed feelings of regret about some of their decisions. Shojoon, for example, thought these decisions were *"not all successful, but a little is better than nothing"* (Shojoon, I:p.2)*, "because the availability at the centres was very limited. [She] had financial problems, which constrained [her] decisions"* (Shojoon, I:p.7). Fadwa experienced feelings of regret about her decision at the beginning, because she felt that she had *"made [her] son tired as well as [her]self"* (Fadwa, I:p.2). However, she thought that she had developed the ability to make better decisions, and she felt *"comfortable"* because she had done *"[her] best with [her] son."* She felt that her *"decisions were good"* (Fadwa, I:p.4). Fatin experienced a feeling of regret about some of her decisions for her first son. She regretted *"using Chinese acupuncture, oxygen therapy, audio, and sensory integration training,"* because *"these were all expensive and useless"* (Fatin, I:p.5).

Athari expressed a mixture of satisfaction and regret, saying: "*Sometimes, [she] have doubted what [she] have done. [She] felt sceptical about [her] decisions at the start."* However, she went on to say: *"When [she] recall what [she] have decided for [her] son, [she] thank God that what [she] have chosen was right. [She] bounced from one choice to another. [She] do not regret anything"* (Athari, I:p.4). She described her choices as being guided by her instinct as a mother and said, *“a mother knows.”* Her only regret was from before she went to the UK, because she was not sure about her son’s condition before this, and thus *“could have done things differently.”* But she also felt that it was not her fault for not doing things differently, as she did not have clarity about his condition. She stated that she was *“not sure what Mostafa’s needs”* were or *“what programmes were suitable for him”* and she *“would have doubled the sessions”* if she knew then what she knows now (Athari, I:p.6).

The preceding examples show how mothers valued their decisions in a country with limited resources, as they stated in their stories. Feelings of regret were apparent in some stories; however, the mothers continuously thought about their decisions for their children’s educations. They reported that mothers were still not able to decide which school their son should go. For example, Athari mentioned that she still *“discover(s) new things about ASD”* (Athari, I:16).

To sum up, mothers of children with ASD searched for therapies and educational placements for their children with ASD. They strived for various solutions to find a ‘cure’ for their children’s condition. When they tried to find a placement for those children, mothers encountered rejection from schools, centres, and public services. In addition, the preceding presentation of the findings also highlighted the fact that mothers had different perceptions of the centres or schools that their children were attending. The findings also encompassed some strategies that mothers used to investigate their preferred placements for their children with ASD.

5.5.4 Mothers’ strategies to support their children’s development

18 mothers out of the 25 showed some independence in finding or creating support, intervention, or resources for the development of their children’s skills. They described how they tried to overcome a lack of resources by creating their own strategies to support their children’s development. There was some commonality in using strategies that supported children’s development, such as the use of everyday experiences to promote understanding and comprehension of their surroundings. Not all mothers mentioned the strategies they followed for their children with ASD.

Activities to support the child's development	**Mothers (n = 18/25)**	**Types of development mothers reported**
Day-to-day activities	Athari, Fatin, Fadwa, Ibtihal, Thana	Speech development Reading and writing Improving social skills Improving communication skills Improving concentration Reducing hyperactivity Reducing tantrums
Using educational games and toys	Anfal, Aseel, Ibtihal, Sondos, Samaher, Razan,	
Buying books	Anfal, Maha, Zulfa,	
Taking them to parks, beaches, etc	Aseel, Ibtihal, Nirmin, Shahad, Shojoon	
Creating a social atmosphere	Fadwa, Fatin,	
Involving siblings	Aseel, Fadwa, Narjes, Shahad, Shojoon, Rahaf, Zeina	
Rewarding good effort	Athari, Fatin	
Displaying physical affection and love	Athari, Fatin, Rahaf, Sondos, Zeina	
Avoiding things that affect their development (phones and TV)	Athari, Ibtihal, Nirmin, Sondos,	
Continuous contact with the school/centre	Athari, Aseel, Fadwa, Ibtihal, Shojoon,	
Being involved in developing their child's education plan	Athari, Fadwa, Shojoon	
Hiring private specialists to support their children's development at home	Narjes, Shahad, Thana	
Attending conferences, workshops, diploma in special education	Fatin, Fadwa, Razan, Zeina	

Table 5.5: Example of mothers' activities to support their children's development

As shown in table (5.5), a common strategy used by mothers at home was the use of **educational games and books** and **day-to-day activities** in order to support their children with ASD. They implemented these strategies which they thought played an important role in improving their children's conditions. According to some mothers, they learned about the best approaches through their searches on the internet, which they tried, adapted, changed, and worked on as much as possible.

Anfal, Ibtihal, Mariya and Sondos found that the use of day-to-day activities, such as helping them in the kitchen, or cleaning the house helped them in developing speech, or developing their life skills. This helped them in developing their children's speech, as well as in teaching them reading and writing. Aseel, Nirmin and Shahad reported that it was essential to think of ways of reducing their children's tantrums. They said that effective ways of reducing these tantrums included walking around or taking them to the beach. For example, Nirmin explained that she *"was able to reduce [her son's] hyperactivity by taking him every day outside the house and walking around with him"* (Nirmin, S).

Athari's main focus was to help improve her son's social skills, as her *"main interest was for [her] son to socialize with the world"* (Athari, S). She also included **family members** to help her in supporting her son, such as his father, who *"reads stories for him or they play with each other"* (Athari, I:p.7). Fadwa also shared her use of day-to-day strategies to support her son through his **siblings**, saying that she used *"group play as a family, sharing responsibilities"* (Fadwa, I:p.6). She *"gathered children to play with him, and he would learn skills from them"* Fadwa and Rahaf found that this strategy helped their children to develop their communication skills.

Fatin purposefully created **a social atmosphere** and invited children to play with her son. Besides this, she also started supporting him on how to communicate with others and integrated him with some neurotypical children. The training at home was carried out through daily activities for the children, such as memorization of the Quran and teaching life skills. *"Group activities, such as playing ball games,"* were also used to socialise him (Fatin, I:p.4). Fatin argued that children with ASD *"need life-skills training, one-to-one activities, stories, photos, and sounds to help their development"* (Fatin, I:p.10).

Four mothers reported that **displaying affection and love, and using cuddles** were more effective than being strict with their children. Fatin outlined how she *"always use[s] love and cuddles"* and encourages *"good work from [her] child,"* also using *"massages to comfort him"* (Fatin, I:p.4).

Ibtihal described the strategies that she used at home to support her child's development. *She "prepared a special room for him and put educational books there. I used to take my son to walk to the public parks and beach*" (Ibtihal, S). She felt this had a good impact on him because, at the end of her story narration, she said that she helped him to develop and become a typically growing child. She said that these strategies helped to reduce *"the hyperactivity, increase his concentration span, his communication skills, and his desire to learn and to boost his speech"* (Ibtihal, S).

Zeina repeatedly spoke in the interview about the factors that she found useful in supporting her child's progress. These factors were the strategies, the time available, and the environment. In order to help her son's understanding she found and tried different strategies, such as the use of repetition and one-to-one training. She also spoke about choosing a suitable time for training (not when he is angry, hungry, or upset), and there should be acceptance of it from him. The environment in which the training took place was also a significant factor in the training itself, as *"Obaid likes to be in an environment full of fun and attractions, such as music and rhyme"* (Zeina, I:p.9). Zeina found that these strategies affected her son positively.

Some mothers felt that the cause of their child's condition was affected by **the overuse of electronic devices**; thus, as they sought to improve their children's development, they thought of stopping the use of these devices. They expressed good results in preventing them from using these devices, as mentioned by Athari, who *"stopped the use of these electronic devices, and [her son] started to develop his behaviour in a better way"* (Athari, I:p.7). She said that she currently uses electronic devices as *"a kind of reinforcement for good behaviour,"* or to *"use a certain application that might help him in* *comprehending the world around him"* (Athari, I:8). Similar results were mentioned by Ibtihal, Nirmin, and Sondos in their stories (Phase 1).

Another common strategy mothers used to support their children's development was **continuous contact with the teachers** and professionals in the school or centre. Athari, Aseel, Fadwa, Ibtihal and Shojoon stated that they frequently contacted the teachers and asked them to send their comments about their children's progress or drawbacks. Ibtihal *"asked the specialist to give [her] instructions on how to deal with him"* (Ibtihal, S). Athari said that her communication with the centre and the school was in order *"to follow the same way they are following"* (Athari, I:p.5). She also wanted to make sure that the teachers and specialists *"adapt strategies to suit Mostafa's needs,"* because sometimes, she felt her son *"was not ready yet for what they wanted to do"* (Athari, I:p.7).

It could be said that through communication with the school or the centre, mothers seemed to feel that they could keep up with the development of their children. They felt that they were better able than the centre to identify their children's needs in order to help their development. An understanding of their children's needs was reported to be essential for mothers in order to evaluate their children's needs and inform the teachers or specialists. Besides this, it could also be interpreted as being indicative of good relationships between mothers and specialists/teachers in the centre/school. Mothers underlined the importance of following up specialists' work with their children and applying everything recommended by the centre or school to help their children. This follow-up helped to support the children's development. It also seems that mothers' ideas were accepted and listened to by specialists because they reportedly asked mothers to come for a meeting in order to set plans for the children, and they continuously communicated with mothers. "*They continuously invite us as parents to attend meetings and workshops*" (Aseel, I:p.7).

Some mothers said that the best way to support children with ASD was to treat them as neurotypical children, or in a 'normal' way. Rafif reporting dealing her son *“in a very ‘normal’ way, without thinking of him as a child with special needs.”* She treated *“him the same as any child who is normal*” (Rafif, S).

Some mothers felt that in order to be able to support their children with ASD, they could learn the best strategies by attending **workshops and conferences**, and Fatin and Razan studied for diplomas in special education. Zeina, Fadwa, Fatin and Razan attended different courses and programmes, and they decided to choose to attend an intensive program in special needs. Fadwa took *“different courses, which [she] adapted in [her own] way to teach and train [her] son”* (Fadwa, S).

To sum up, mothers of children with ASD appeared to adopt a range of different strategies in order to support their children’s development. Many mothers found that these strategies helped their children to develop their communication skills and speech, and for some children, mothers stated that they helped the children to develop some academic skills such as reading and writing.

5.5.5 Mothers’ perceptions of their lives with a child with ASD

When comparing the results of the different mothers’ story narrations, interviews and building-rapport days, I found that there were commonalities between the mothers with regard to their perceptions and feelings about their lives with a child with ASD. Mothers were more expressive about their feelings in interviews than in story narrations, which could be because one of my interview questions was about their feelings towards their children with ASD. I felt that in many narrations, they held back their feelings (perhaps because it was not one of the prompts), whereas in the interviews, emotions were more apparent, for example, and some mothers reacted emotionally by crying when asked about their experiences with their child with ASD.

Most mothers wrote and spoke about experiencing mixed feelings about their lives with their child with ASD. They repeatedly expressed feelings of shock and sadness when learning about their child’s condition. Mothers’ feelings about the diagnosis were discussed previously in part (5.2.1).

20 of the 25 mothers reported feeling that they had a difficult life, attempting to do their best for their children with ASD. Although many of these children showed a high level of development, mothers stated that they felt that having a child with ASD had made their own lives difficult, and that they had to face many challenges. For example, it was difficult for Athari to describe her life as balanced: *"I do not know if you could look at it as a balanced life or not, because every day is hectic. From early morning to evening, I am running from one place to another".* She said that *"this adds pressure"* on her, and she *"always feel[s] that [she is] under pressure."* She also reported feeling *"exhausted"* and that she did not *"have a social life like before"* (Athari, I:p.13).

Maha, Mariya, Nirmin, Somood, Rahaf and Rafif also described their lives with their children with ASD as *"difficult."* Rafif *"had encountered many difficulties at the beginning, but [she] did not stop"* (Rafif, S). For Shojoon, the situation was more complicated because she had two daughters with ASD and a husband she described as unsupportive. She reported that "*there is always tension in all of the house."* She felt *"disappointed when [she was not] able to deal with [her] daughter,"* and that *"there [was] no support from [her] husband"* (Shojoon, I:p.9). She also felt that she *"used up all of [her] energy."*

Somood highlighted feelings of helplessness: "*[She] need someone to help [her] and teach [her] how to deal with him. [She] cannot do it myself. [she is] disappointed [she] is not educated, and [she does] not know how to deal with a child like him. Sometimes, [she feels] helpless. [She feels] that there is no solution to his condition. [She] cannot express [her] feelings. [She feels] that no words would express the feelings [she has]"* (Somood, I:p.2).

Sondos was also facing a challenging life with her child with ASD, though she was able to enrol him in a mainstream school. In her own words (written in English), she said: "*Being a mother raising a child with ASD is a challenging role. This is because [They] are dealing with a human being who wants full attention. This creature is physically with [them], but mentally, he is far away from [them]"* (Sondos, S).

These mothers found it hard to define a balanced life for themselves as a result of being a mother of a child with ASD; however, they often talked about how they had come to accept their lives with their children, because there was no alternative.

5.5.6 Mothers' feelings about their child's development

Almost all of the mothers reported positive feelings towards the significant developments in their children's condition, except for Somood, who felt that her son's condition was worse than before. Four mothers described how they were able to develop their children's conditions to be similar to neurotypical children of their age. This was illustrated in the accounts of Jumana, Rafif, Mariya and Zulfa. These mothers seemed to believe that their children were '*cured*' from being children with ASD and could be described as typically growing children. Jumana said that, with her continuous support, *"[their] son has developed greatly more than other children with ASD. He will grow up and practise his daily routine normally"* (Jumana, S). Rafif also said that she was able to get her son *"out of the world of ASD. [She] could see the change."* Though *"he is behind his peers, a final diagnosis proved that [her] child does not have ASD anymore" (*Rafif, S).

Eight mothers thought they had noticed improvements in their children, especially in their speech, responses to instructions, and ability to depend on themselves in life skills. Athari reported how her son *"could depend on himself, especially to go to the toilet, because he was able to go to the toilet by himself only at the age of 7"* (Athari, S).

These developments had positive effects on mothers' feelings. According to the mothers, they might have some feelings of depression, but generally they felt happy about their children's development. Fadwa said: She feels "*happy because of all the achievement [she] accomplished with [her] son. [She] also feel worried but this does not stop [her]"* (Fadwa, I:p.5). This also makes them feel positive about their children, because if *"he can go to the toilet, then he can* *do anything"* (Fatin, I:3). Shahad and Shojoon also expressed feelings of happiness and satisfaction regarding their children's development.

Some mothers said that their children had good potential and only needed someone to support this. For example, Maha found out that her son is *"a clever boy. Jamal's concentration and memorization are good, and he retains and never forgets things he learns"* (Maha, S).

Sondos shared her feelings in the story narration phase about when she heard the first word from her son. She recalled this experience: She *"still remember[s] the first word came from his mouth (cat). [She] could not believe that [her] son started saying words."* This made her think positively, despite his delay, and she felt that *"it [was] a good sign that he started talking,"* which gave her hope that *"his ability to speak will develop"* with the intensive training. In the last few years, Sondos was able to notice how her son *"has been progressing."* In terms of education, Sondos expressed her *"strong belief"* that her son *"deserves to have the chance to go to a school and study as other normal children"* because *"he has the potential; what he needs is a professional educational environment with a specialized teacher to provide him the proper education"* (Sondos, S).

Though mothers adapted themselves *"to live with ASD,"* they expressed mixed feelings about their children's condition. They continuously expressed difficult feelings such as confusion "*when [they] do not know how to deal with him. ASD was not clear for [them]"* (Shahad, I:p.5). They had feelings of worry *"about [our child's] condition,"* which affected their lives, as Thana reported that she *"could not have a good sleep, and did not eat well"* (Thana, I:p.15). Mothers also repeated feelings of guilt and sadness that they had not done enough for their children, and sadness about their children's conditions. When mothers reported feeling sad, some stated that they *"developed strategies to get [them] out of [their] sadness,"* such as thinking about *"success in [their] son's development"* (Athari, I:p.16). Thana, for example, tried to *"compare Majed's condition to many children with ASD,"* feeling able to *"say that he is better than many other children"* (Thana, I:p.14). In this way, she said that thinking positively about how her son had developed *"helped [her] relax"* (Thana, I:p.14).

Zeina reported that she faced many challenges, especially as she was taking care of her child by herself. However, in her story narration and her interview, she expressed more positive feelings about his development, as he had improved *“in many life skills (but not verbal skills).”* She reported that since he was *“managing his needs by himself”* and *“his sensory challenges had also subsided,”* this made her life more balanced (Zeina, S).

Athari, Fadwa, Fatin, Maha, Sondos, Shojoon, Shahad and Zeina expressed positive attitudes towards the levels of development in their children’s conditions. There might be some difficult feelings, but they felt positive that their children had significantly developed. However, for Somood, the experience was different. She expressed her (negative) feelings towards her son’s development, saying that she thought he *“was growing older without any progress in his condition”* (Somood, I:p.3). There was a feeling of guilt, which was apparent in her interview, as she said: *“[she] would have started earlier, and [she] would have enrolled him earlier in school. Maybe he would be better. Maybe he would have developed better. [she] thought that it would not be good for him to be mixed with other children with different disabilities who were worse than him.”* However, she stated that they had reasons for not starting earlier*,* namely their *“financial situation.”* Somood *“did not start with [her son] until his brother started work”* (Somood, I:p.4) so his brother could pay the centre fees. Somood described her son’s condition as “*worse than before”, saying: “Tariq used to be quieter. [she] do not know how to deal with him. He is always embarrassing [her] in front of [her] neighbours. This is [her] biggest problem with them”* (Somood, I:p.6).

To sum up, mothers in this study seemed to be appreciative of the development of their children, which made them express positive feelings of being happy because of what they had achieved with them. They emphasized feelings of comfort and satisfaction with their children’s development. Some mothers spoke positively about their children’s development, though they described some difficulties of living with a child with ASD. It appeared that mothers experienced a mixture of positive and difficult feelings when talking about their child's development. They are happy and satisfied with what they have achieved, but they are worried about what might come.

5.5.7 Mothers' perceptions of the services available for children with ASD

Almost all (23) mothers in the current study expressed a **negative** perception in their accounts of the available services for children with ASD in Oman. Only two mothers talked **positively** about the centre their children attended, and two mothers did not talk about the services. For Aseel, Nirmin and Shahad, the centres that their children attended were reported to be doing well with them, and their children had developed since joining the centres. For example, Nirmin reported that her son *"has improved and changed in the centre because they know him better than us"* (Nirmin, S). The reason for this, she noted, was that the specialists in the centre were *"very supportive, working hard with him,"* and they regularly sent her feedback about her son's development.

For Aseel, it seems that she was satisfied with the services available for children with ASD in Oman because she expressed positive feelings about the centre and the services provided by the MOSD, such as funding and public centres. However, she said that she did not have much information about the services provided by the MOE. Aseel tried to be fair in her judgment about the centre her son attended prior to the current one, though her son did not develop well there. Aseel argued that *"it is a good centre and many children have developed in it. Just because Marwan did not develop there, it didn't mean that the centre was not good"* (Aseel, I:p.5). She also expressed positive feelings about the second centre and said that she was *"satisfied because they have swimming classes and horse riding."* Another reason for her satisfaction was that they *"conduct beneficial workshops for parents"* (Aseel, I:p.7). In addition she described the effort that the MOSD made with children with ASD as *"good effort"* (Aseel, I:p.7).

Fadwa also seemed to be satisfied about services such as functional therapy, whereas other services like speech therapy were not good. However, Fadwa thought that the services available for children with ASD were limited, saying that she had not *“found many educational or training services in [my] country. There are some services, but not many and health services are limited. There are unsuitable integration classes for children with ASD because of unqualified staff, unsuitable atmosphere, and unsuitable plans”* (Fadwa, I:p.6). She also thought that *“there is a need for programs for mothers in order to train them in the skills needed for their children, as well as special programmes for mothers in order to cope with stress and pressure*” (Fadwa, S).

The mothers’ accounts referred to some **services provided by the MOSD**, regardless of whether or not they seemed to be less satisfied with them. The MOSD offered services such as funding children’s education in the private centre, issuing a ‘disability card,’ that helps children in different places, and it is also managing the public special centres and supervising all private special centres. These services were mentioned in some mothers’ accounts, such as Sondos’, who *“managed to get funding from the MOSD”* (Sondos, I:p.8). Shahad was also able to get some services such as *“funding, the disability card for the child, and a monthly allowance*[*]*”* (Shahad, I:p.7).

However, 23 of the mothers expressed negative perceptions of the available services for children with ASD in Oman. Even though they managed to access some services, they perceived these services as limited and not supporting their children’s development. Many mothers expressed their perceptions with the phrase *“no services.”* This phrase was illustrated with examples such as *“no schools”, “no health services”, “no centres for adults with ASD”, “no support”, “no National Centre for ASD” and “no individualized plans.”* The word ‘*no*’ was mentioned 19 times by 19 mothers in relation to services, even though they mentioned that their children were going to special centres, either private or public, or could access some services. This suggests that mothers considered that these services were not sufficient. Athari expressed this in her interview, saying that she “*cannot see many services offered by the MOSD, except the rehabilitation services. They pay for these sessions even if it is in a private centre. They have some services, but they are not enough”* (Athari, I:p.14).

---

[*] A salary for each child

Sondos appeared to be upset about what was offered to children with ASD in Oman. She thought that children with ASD *"do not get the appropriate care in [Oman]."* She thought that *"in some places, there are not any rehabilitation centres."* The Ministry, which supervises these centres, was not efficiently fulfilling its role; for example, there was *"no available transportation"* and *"families complain about the services offered by the MOSD and about the tuition fees in private schools."* The situation, she mentioned, was the same with the MOE: there *"is not adequate supervision for those schools. Schools are not being supervised, and the children with ASD are the victims"* (Sondos, S). MOSD permits *"private centres but does not supervise them, and they make the private centre's work difficult*" (Sondos, I:p.7).

When mothers got placements for their children with ASD, they were often not **satisfied with the services provided** for their children in these schools or centres. Some mothers noted the problem of schools not being able to understand the needs of children with ASD. For example, Anfal stated that children with ASD have *"limited abilities in education, and the curriculum of private mainstream schools does not fit their abilities. Educational methods should be varied for every child according to their potentials and abilities"* (Anfal, S).

Narjes also felt that *"centres in Oman are poorly equipped and operated, and they follow a very poor routine imposed by the MOSD, so children do not improve"* (Narjes, S). These centres are *"all the same",* she commented. The reason for describing these centres as worse was because, to Narjes, *"they [seem] constrained by the MOSD's rules*" (Narjes, I:6). Narjes ultimately felt that "*the centre that [I was] looking for does not exist in Oman"* (Narjes, I:p.13).

Rahaf and Zeina reported similar thoughts about the centres in Oman. Rahaf reported that there was *"a lack of rehabilitation centres in [Oman],"* and that these centres *"do not help a child with ASD to change tangibly"* (Rahaf, S). Zeina also said that *"the atmosphere in the centre was not good"* for children with ASD. The centre *"did not take care of him, and many times did not understand"* her son's needs: *"They were unable to understand him, and there was no continuous care for his needs*" (Zeina, I:p.5).

Mayada and Shahad expressed similar **views about public special centres**, in that they failed to provide quality services for children with ASD because they were trying to accommodate children with a range of disabilities. The centre, Shahad noted, is *"crowded with children, and each specialist has 60 children. The activities done in the centre are not suitable for a child with ASD. There are general plans for all children and no individualized plans."* This made Shahad say that *"even if she never found a place for [her] son, [she] would not take him to these centres"* (Shahad, I:p.8).

There were some **actions taken by the MOSD and MOE** with regard to the education of children with ASD. These was mentioned by some mothers, who said that they played an essential role in demanding and requesting action from the government. Still these actions did not fulfil the needs of children with ASD in the country.

On this topic of **mothers' perceptions of the services available for children with ASD**, they varied in their accounts. Most of them thought the services were limited or the quality of services was low; however, some mothers spoke positively about the services provided in the centres and by the government. In general, though, most mothers seemed not to be satisfied with what was provided by the government in Oman for children with ASD.

5.5.8 Family and societal support

A common theme around support emerged in mother's stories and interviews, which was divided into three types: 1) **family** support (which consists of a mother, her spouse and her children, 2) **extended family** support (which consists of grandparents, aunts, uncles and cousins), and 3) **societal support**, (which consists of friends, wider relatives, and members of wider society).

Six mothers' stories hinted to some degree, that their **spouse and family** supported their strategies to develop the skills of their children with ASD. These mothers, for example, said that they were *"very supportive"* and *"cooperative"* (Athari, S). The family members shared *"responsibility"* towards their children with ASD, and Narjes reported that *"the housemaid is a great asset"* to her (Narjes, I:p.9). Some families share responsibilities to develop their children's *"behaviour and teach [them] some simple skills"* (Somood, S). Somood argued that her *"two daughters understand their brother and help [her] to take care of [her] son"* (Somood, I:p.4). Athari's spouse supported her decisions in finding the preferred placement for their child. Her husband supported *"all the plans [that she] set for Mostafa's education."* She felt that *"he supports [her] in every step*" (Athari, I:p.9). Narjes also spoke about how they *"discuss and set plans as a family"* (Narjes, I:p.9). Sharing responsibilities was seen as an asset for mothers taking care of their children alongside performing their usual *"life activities such as prayers, shopping, cooking, and even visiting friends normally"* (Narjes, S).

On the other hand, Shojoon, Sondos and Thana spoke about not receiving support from their spouses. This seemed to add stress and pressure to their feelings about their children with ASD. Shojoon felt that *"there [was] no support from [her] husband"* as *"he has his own life without thinking to be involved in his children's lives"* (Shojoon, I:p.5). To some extent, Shojoon and Sondos blamed the child's lack of development in a specific area on their spouse. Sondos felt that her *"son's lack of communication with society is caused by his father's carelessness"* (Sondos, I:p.7). Thana also thought that her husband was *"ignoring"* her son, although she said towards the end of the interview that over *"the last two or three years, he started to take some responsibilities for Majed"* (Thana, I: 8). She described her marriage as *"unfair,"* and said that she lives a *"complicated"* life (Thana, I:p.3).

17 of the 25 mothers reported how their **extended family members** supported them in taking care of their child with ASD. This had allowed them to cope better with stress and pressure thus, they noted, enabling them to make better choices for their children with ASD. Having an *"understanding and cooperative"* extended family helped mothers *"in making the situation comfortable because of the presence of a child with ASD who needs monitoring and is not aware of the danger. [They] need continuous care and attention"* (Anfal, S). Athari, Fadwa, Jori, Jumana, Narjes and Rahaf spoke about how important it was to

recruit family members to support their children's development. They attempted to help their speech, their life skills, and *"they treat him as a very 'normal' child"* (Jumana, S). Rahaf said that she "*cannot forget that [her] mother has made countless attempts in teaching him to repeat words after her"* (Rahaf, S). Family members also accepted children with ASD, and they *"sympathize" with* their condition (Narjes, S). Mothers also noticed that everyone *"never got annoyed by [the child with ASD], even though [they] broke everything around [them], because of [their] hyperactivity and unconsciousness"* (Rahaf, S). They also mentioned that their extended family encouraged their decisions and supported them *"financially"* (Shojoon, I:p.8).

However, some mothers described how they came across a lack of awareness from the people close to them. They narrated various examples or events involving their family members. Mothers thought that this was because of a lack of awareness of the condition of ASD. Some family members "*accused [mothers] of negligence and carelessness"* towards their children. Unlike other mothers, Ibtihal experienced negative behaviour from her in-laws, and she *"felt that they did not want [her] child because of his behaviour." They called her son "crazy" or said that he "had no mind"* (Ibtihal, S). Nirmin also faced a similar situation from her family, as they *"never accepted him because of his continuous movement and fluttering and screaming"* (Nirmin, S).

The data also indicated the experiences and perceptions of mothers about **societal support**. Many mothers felt that people were not informed about ASD and the meaning of this condition. Nirmin, in her story, also wrote about how *"some people mocked [her family], some wished not to have a child like [her] son, others felt sorry for [them]",* feeling that *"society has been unfair with [them]."* Shojoon described the society as *"ruthless"* as they *"never understood what we were going through."*

Shahad also *"faced many problems with the surrounding society because they were not aware of this 'disease.' "People* thought her son was *"a crazy person,"* or that he *"had a mental problem.*" They were not able to go *"out to public places" as a family* because *"everyone stared at [their] son as if he was alien"* (Shahad, S).

Sondos spoke about how people treated children with ASD as if they have *"mental problems,"* saying: *"Society cannot accept them. For society, they are horrible people. They look at them as if they are from a different planet. Honestly, in my society, [she is] sorry to say that there are many people, including those who are educated, who are still not aware of autistics. If it happens and they see any autistic child behaving strangely, they immediately say that this child has misbehaved"* (Sondos, S).

Because of these responses and this behaviour from society, mothers were *"affected psychologically"* (Athari, S), and felt an "*increased mental burden"* (Shahad, S). Razan could not tolerate people staring at her daughter, which in turn "*made [her] move from [her] town to another town"* (Razan, S). This shows the impact of society's understandings and perceptions of ASD on mothers. The way that wider society looked at the children with ASD *"caused painful feelings"* (Shojoon, S).

Interestingly, Maha, Fadwa, Rahaf and Shahad attempted to educate the people in their local society about the meaning of ASD, and how it affected their children, *"how to deal with [them] in the best way, and how to understand [their children's] actions"* (Fadwa, S). Maha also tried *"to make [her] relatives understand that Jamal was a child with ASD and explain to them its' meaning*" (Maha, S).

Some mothers said that they were personally blamed for the children's behaviour. They felt that they were judged by society quite harshly and that people were generally intolerant of their children's behaviour. Sondos felt that people in wider society *"were blaming [her] for [her] child,"* and that she *"needed to teach him how to behave well"* because she *"used to be in that situation where [she] was blamed for [her] child's behaviours"* (Sondos, S). Similarly, Zeina spoke about how *"the society is not aware of ASD"* and about the *"negative comments to show that [she is] not doing [her] job towards [her] son"* (Zeina, I:p.17). She felt that others judged her parenting skills.

On this topic of **family and societal support**, mothers spoke about the support they received from their closer family members, as well as their extended family. Fewer mothers spoke about an unsupportive spouse compared to the majority, whose spouses shared responsibilities and supported their decisions about their children with ASD. Most mothers agreed that society was not supportive, and that society sometimes blamed mothers for their children's behaviour.

5.5.9 Hopes and concerns for the future

The data gathered through the stories and interviews illustrated mothers' **hopes and dreams** for the futures of their children with ASD. Their feelings about the future were mixtures of hope and worry.

Mothers seemed to look forward to the future with the hope that their children would one day overcome their difficulties and live independent lives. Aseel said: She *"hope[s] that one day he will be normal as he used to be when he was two years old.* She "*hope[s] he becomes independent"* (Aseel, I:p.6). Some of them hoped to see their children 'cured' of this condition, as Shahad expressed: She "*hope[s] he recovers from his condition and see him develop. [She] hope[s] he goes to a mainstream school, learns to depend on himself, and understands what's going around him"* (Shahad, I:p.10). She has *"hope that [her] son, one day, will be a 'normal' child like many other children"* (Athari, I:p.16). Some even wished to see them become doctors or engineers, like Fatin, who said: She *"hope(s) for Khozam to become a doctor, and Hassan, a dentist"* (Fatin, I:p.11).

In general, most mothers hoped that their children would *"be independent in life skills such as washing [themselves], going to the toilet, feeding, cleaning, and wiping."* Marwan hoped that her son could *"know his needs, such as if he is thirsty or hungry,"* saying: She *"hope(s) he knows the danger, and hope[s] he can behave well in gatherings, so that [they] can go out with him without being scared of his tantrums. [She] hope[s] [they] can travel with him"* (Narjes, I:p.12).

Mothers' hopes about the future varied from wanting their child to be independent in life skills, learn a skill or craft, or have *"a family, kids and income"* *(*Fadwa, I:p.7), to hoping that they would learn how to *"read and write*" (Shahad, I:p.3). The most straightforward hopes of these mothers for their children with ASD were to see them being independent, like other children their age, or to hear them speaking. Narjes said that she "*strongly believe[s] that one day, [her] son will speak, because he hums songs*" (Narjes, I:p.12).

Mothers in the study expressed **concerns** about the future of their children with ASD. They were anxious about the unknown future, especially after their own deaths. The following examples illustrate mothers' concerns about the future. Aseel said: Her *"main concern is what will happen to him if [she] die[s]*" (Aseel, I:p.6). Mothers expressed a constant worry about the future of their children, and *asked, "How is he going to be in the future? How he is going to deal with life. How is he going to be after ten years"* (Somood, I:p.7).

Shahad's main concern was about adulthood, perhaps because her son was 14 at the time of the interview. Her *"concern is when they reach the stage of adolescence and after that. Adults have to sit at home facing great problems and what has been developed during childhood will now collapse"* (Shahad, S). Shojoon was also worried about "*adulthood because they are girls. Many changes will happen to their bodies"* (Shojoon, I:p.10). She was scared that "*people might do something wrong to them"* (Shojoon, I:p.8).

For Athari, she tried not to think about the future, and though she had some concerns, she did not want to exhaust herself with thoughts about the future. She said: She is *"leaving this to God. [She] cannot change the future.* (Athari, I:p.16). She is still not sure about the future but feels that she *"can manage [her] stress."* She feels *"capable of facing challenges,"* but she felt that she did not *"know about the future, because Mostafa is still young and [she is] not sure about how [she will] face the challenges that might come up"* (Athari, I:p.12).

The feeling of worry and uncertain about the future was also apparent in Zeina's story, as she repeatedly used phrases such as she does *"not know"* and she is *"not sure,"* and ended with she is *"not optimistic about the future"* (Zeina, I:p.10), saying: she is *"worried about how slow his progress will be. [She is] worried about his future* (Zeina, I:p.13).

The mothers in this study showed concerns and hopes for their children with ASD, and they were also anxious and worried about the unknown future that faced them. These concerns varied from finding an educational placement for them, to them having the ability to live independently. There were also some concerns about what would happen to their children after they, the mothers, die. Mothers expressed concerns about whether their young children would be supported, secured, protected, or whether the community would take advantage of their vulnerability. They hoped that their children would be happy and accepted in the community. Mothers wanted to see their children growing up and becoming independent.

5.6 Summery of chapter five

The findings in this chapter presented summaries from three phases of data collection (written/recorded narratives, interviews, and three building-rapport days) and a detailed cross-case analysis. Mothers initially described experiencing feelings of shock, and how they had reacted emotionally at the time of their child's diagnosis. They also said how they needed to find a solution for supporting their child's development. They had attempted many therapies or strategies to increase their child's development. They had also tried to find an educational placement that might suit their child's needs, whether a centre or a school with additional support. The mothers' accounts suggest that they struggled to find the best place for their children. The findings also suggest that mothers faced challenges in their lives with a child with ASD and that they had to face challenges with family and community's understanding of ASD. The mothers' perception of ASD seemed to encourage them to accept their children's condition and try their best to support the development of their children with ASD. They also had worries about the future of their children.

Chapter 6: Discussion Chapter

6.1 Introduction

Drawing on the findings presented in the previous chapter, this chapter discusses the results in relation to the aims of the study with particular reference to the Omani context and the existing literature. The chapter, thus, shows how the findings of the current study can contribute to an understanding of the mothers' experiences, perceptions and feelings about their lives with their children with ASD and the educational decisions and choices they make for these children.

This chapter is divided into five main sections. The first section discusses motherhood and the emotional responses of mothers to their children with ASD. These, which include emotional responses to three main areas, namely diagnosis, development and hopes and concerns about future. The second section discusses roles and responsibilities of mothers of children with ASD. These include their roles as primary caregivers, their involvement in their children's education and their seeking-diagnosis behaviour for their children's condition. The third section is about the influences on mothers' educational choices and decisions; this is divided into family, child and services. A fourth section discusses services in terms of quality and availability, and the final section is about levels and types of support. It must be noted that because these themes are interconnected a high degree of overlap is unavoidable.

6.2 Motherhood and children with ASD

The findings of this study complement and extend previous research by examining mothers' experiences, perceptions and feelings about their lives with children with ASD and the diagnoses they received. Mothers in Oman, at least those in this study, seem to have emotions similar to those of many other mothers worldwide (Pearson & Meadan, 2018; Boshoff, et al., 2016). This may be because ASD is a global 'disorder' that does not differentiate between places and people and manifests similar 'symptoms' in different societies (Mandy et al., 2013).

This section discusses the impact of being a mother of a child with ASD in relation to the mothers' emotional responses, the roles taken on by mothers and their thoughts about their children's future. Different feelings were found to apparently determine the mothers' ways of taking care of their children with ASD.

6.2.1 Emotional Responses

A range of emotional responses was reported by Omani mothers in the current study regarding their role as a mother of a child with ASD. These emotional responses will be discussed in relation to three different phases/stages in the child's life: the diagnosis process, the period as the child develops and concerns about the future.

These feelings are more likely to be understood through Kublar-Ross' (2009) model of grief that is consisted of the five stages: denial, anger, bargaining, depression and acceptance. The findings from the current research showed that some mothers may undergo some/all stages of this model. The feeling of shock and denial was also reported in Rogers (2007), as these feelings were common when parents faced the diagnosis and loss. They may also experience the feeling of anger when they start to live the 'actual' reality, which in many cases is not the 'preferable' reality, and this leads to the anger. Mothers also may experience the bargaining stage when they start to negotiate their life to be back to how it was before the event of their child's diagnosis. There are also feelings of helplessness and hopelessness which may cause depression. The final stage is the acceptance stage when mothers' emotion starts to stabilize about their child's condition. These stages are not linear, and mothers may experience some of these and others may not (Kublar-Ross, 2009). Therefore, I will discuss these based on three stages of the mothers' experiences, the diagnosis process, as their children develop, and mothers hopes and concerns about the future.

Diagnosis process

Before they received an official diagnosis, a range of feeling was mentioned by the mothers in this study, similar to those laid out by Rogers (2007). For example, they had feelings of confusion because they did not know what was happening to their children; feelings of denial because they did not want to believe that their children had a problem; feelings of fear because they wanted them to be typically developing – "denial and shock in relation to the diagnosis and potential loss" (Rogers, 2007, p. 45). This stage is similar to Kubla-Ross', 2009 model of grief. In searching for an explanation for their child's behaviour, mothers in the current study drew upon a range of understandings and used different techniques. Some mothers drew upon previous knowledge and experience – for example, by attributing their child's behaviour to hearing problems or speech delays or by linking it to possession by evil spirits. Some mothers blamed themselves, concerned that they might have caused their children's condition. Some mothers in this research tried to understand their children's behaviour by extending their knowledge through browsing the Internet or reading books, although they did not initially understand that their children's condition was related to ASD as it was not familiar to many of them. This search for an explanation affected them emotionally and could be explained from a medical/ religious disability model's lens, that the problem of their children is within their children (see section 3.2). This finding is similar to that of Gomes et al. (2015) who carried out a review of ten articles published in Brazil and found that parents were emotionally overloaded when they were looking for a diagnosis for their children with ASD. Gomes et al. (2015) aimed, with this review, to describe the challenges faced by families, especially mothers of children with ASD in Brazil, and the coping strategies they employed. The emotional overload, they found, was mainly caused by the diagnostic postponement, difficulty with the diagnosis associated symptoms, and poor access to health service and social support (Gomes et al., 2015). These seemed similar difficulties to those reported by mothers in the current study.

Feelings of denial of the child's condition was one of the more prominent feelings that mothers in the current study reported experiencing during the diagnosis process. Kearney and Griffin (2001) suggested that when parents become aware that something is 'wrong' in their child's development, they may experience feelings of denial, along with feelings of grief, regret and excessive responsibility. In the current study, mothers' lack of knowledge about ASD may have also led to denial. Protracted denial, in the current study, however, seemed to lead to confusion for mothers because, in a state of denial, it would appear to them that the child was simply and unaccountably unable to do daily activities and refusing to participate in early social events, leading mothers to go to doctors over a long period of time, seeking an acceptable diagnosis. From the medial model of disability (see section 3.2), this seemed to affect the mothers' decisions about what to prioritise for their children with ASD that would help them progress and gain skills such as life-skills.

The work of Rogers (2007) is linked to mothers' emotions. Her work explores the complexity of emotions at discovering difference. The 24 parents, in the south of England, that Rogers interviewed experienced similar feelings to the mothers in the current study. These were shock, loss and disappointment, which may lead, in turn, to denial, anxiety and conflict affecting both the parents and the professionals involved with the family. The cause of these feelings could be generated from the pressure of producing 'perfect' babies. Yet in later stages, many of them start to reorganize and re-evaluate their pathways.

In the current study, receiving the unexpected diagnosis of ASD, which, as noted above, seemed to be an unfamiliar condition to many mothers, often started with feelings of shock; some mothers indicated that they were not prepared for such a diagnosis even when their children had showed unfamiliar or atypical behaviour. When mothers finally received the official diagnosis, most of them also reported experiencing feelings of sadness and loss, feeling that they had lost the child that they had been waiting for. The mothers in this study viewed the news of the condition of their child as the loss of a normal, healthy child, as the loss of their 'real child'. Their plans for being good mothers of a perfect child were made no longer viable (Landsaman, 1998). It seems possible to compare the mothers' responses to the diagnosis in this study with the mourning stages that someone goes through when someone significant or close dies, as mentioned above about Kublar-Ross' (2009) model of grief. Rabba et al. (2019) also noticed this in their study in Australia using interviews and focus groups with 13 fathers and mothers of young children diagnosed with ASD. Similarly, a study by Fernańdez-Alcántara et al. (2016), of 20 parents of children with ASD in Spain, identified such a feeling of 'unexpected child loss' as predominant. In this study, it was found that parents may deny the evidence, not wanting to accept reality but instead tending to seek other opinions, other diagnoses. These parents tried to minimise the situation and think of the symptoms of ASD as only a maturational delay. Similarly, mothers in the current study reported emotions of denial, as discussed above, which caused them to look for other opinions and alternative diagnoses, and to hope that in the future their children would recover from the condition. This could be explained that mothers were more influenced with the medical model of disability, thinking that the deficit occurs within their children.

The mothers with a child with ASD in the current study reported being faced with a number of challenges when raising their child. One of the first challenges, as noted earlier, originated with the realization that their child was not developing 'normally' and emotions associated with this continued to persist throughout the diagnostic process, which often spanned a long period of time (from the medical model perspective). Mothers' response to a diagnosis of ASD for their child have be described as a series of stages before the acceptance of disability: denial, grief, rage, regret, deep love and excessive responsibility (Kublar-Ross, 2009 grief model). These responses were echoed in the current study (see sections 5.2.1). However, different mothers experienced the arrival of a child with ASD in the family in different ways due to their own characteristics and other factors that directly affected an acceptance process, such as denial of the diagnosis and feeling that their child did not have what they were told they had. Other mothers felt grief, rage or regret that they might have caused this condition in their child. At the same time, these emotions were mixed with deep love realizing that their child would need them and a feeling of excessive responsibility to help them develop as any other typical children. This is similar to some parents in Rogers' study (2011) who pointed out that the "act of parenting a baby is the bigger task at hand, not the actual syndrome" (p. 139).

Tomiyama et al.'s study (2018) in Kanazawa in Japan found that where mothers' lives were filled with negative emotions, this disrupted their decision making and led to unexpected actions. Mothers of children aged between 63-111 months in the study reported that they would have been more likely to accept their child's condition if they had had a better understanding of the condition prior to having their child. Mothers in the current study similarly talked about the sense of acceptance for their children's condition after a period of time. The current study also suggested similar negative emotions affected mothers' decision making and led to unexpected actions, similar to those reported in Tomiyama's study.

The emotional responses to the diagnosis of their children with ASD at the time of the diagnosis seemed to be significant for the mothers in the current study and seemed that these emotions did not diminish in the years following the diagnosis.

As children develop

As their children develop, mothers continue to experience a range of emotions. For example, in the current study, they reported emotions and associated responses such as grief, anger, exhaustion and stress. These emotions were specific to each individual mother and were prone to change over time. These results align with previous research (for example, Fernańdez-Alcántara et al., 2016; Hayes and Watson, 2013; Wang et al., 2013), which indicated that parents whose child is diagnosed with ASD often experience a series of responses over time such as shock, denial, anger, sorrow, fear, uncertainty, blame and, in some cases, acceptance. Some of these responses were discussed above in the 'diagnosis process' section. Fernańdez-Alcántara et al. (2016) found that the process of grief resolution for some parents was more disruptive than the diagnosis process itself. Many Omani mothers of children with ASD in my study stated that they were confronted with great fears for the future and experienced ongoing high levels of stress. These findings also concur with the findings of other studies, which have reported similarly high levels of stress and, in addition, depression for parents of children with ASD (for example, Al-Farsi et al., 2016, as referred to in the literature review). Al-Farsi et al. (2016) surveyed 220 Omani parents (107 fathers and 113 mothers) of children with intellectual disabilities, ASD and typically developing children. Their study aimed to examine the variation in stress, depression and anxiety among these parents, through the use of a depression, anxiety and stress scale. They found that caregivers of children with ASD have "adverse psychological states that manifest as stress, depression, and anxiety" (Al-Farsi et al., 2016: p. 1950). Other studies have also contended that children with ASD are likely to pose greater pressures on parents than neurotypical children or children with other kinds of disability. For example, Minnes et al. (2015) found that having a child with ASD could lead to increased parental stress. This may be attributed to the level of behavioural problems in children with ASD typically being more severe than those of children with other disabilities (Halstead et al., 2018). These behavioural problems can then affect the social skills development of the children concerned and lead to more intensive care being required from their parents. In addition, the individual child's characteristics can impact the challenges their parents face. The findings of Halstead et al. (2018) demonstrated that even in Western countries, where assistance for children with ASD is better arranged and there are fewer problems for their families in accessing services, such families still face more challenges than those raising neurotypical children. Therefore, the manifestations of the mother's depression, irritability and emotional exhaustion are understandable. In this study, many Omani mothers described caring for their children with ASD as a burden. They talked about experiencing stress caused by a number of influences, such as obtaining a clear diagnosis (as discussed in the previous section), attempting to access services, finding 'treatment' for their children's condition, coping with a financial burden and coping with social relationships with their family and their community. These mothers provided examples of the daily pressures that they experienced over time and stated that they felt emotionally exhausted.

Having a child with ASD in the family can be challenging not only the mother but also for siblings, since it often causes great tensions and problems in the family (Russa et al., 2015; Roffeei et al., 2015). In the current study, it was found that the identification of a developmental problem in a child affected the mother the most, but could cause a crisis and affect the whole family. Having a child with ASD has been found, for example by Lu et al. (2018), to affect the daily contact between family members, with a number of different problem behaviours. These include a lack of eye contact, lack of interest in the environment and the rejection of physical contact, sometimes leading to the child with ASD having tantrums for no apparent reason, or because they did not get something, or did not understand something. Such behaviours during the growth of a child with ASD can contribute to feelings of helplessness and anguish for families and for mothers. Beyond the impact of the diagnosis and the uncertainty and difficulties that arise in everyday life, the very fact of having a child with ASD can cause feelings of helplessness that are hard to express. Roffeei et al. (2015), in their study about parents in Malaysia sharing personal experiences and seeking advice in raising or taking care of children with ASD, found many behavioural changes in the mothers, with problems in self-esteem and ambivalent feelings towards their child with ASD. Parents in a study by Roffeei et al. (2015) even blamed themselves for having those feelings, and so any comment from a mother of a child with ASD about their condition is often accompanied by positive assertions, such as the pride they feel for them or how special they are. These parents made positive comments about their child, along with discussing the stress. Mothers in this study did make other positive comments, too: for example, they viewed having the child with ASD as having improved family cohesion and family relationships.

Mothers in the current study seemed to think they could, through their own efforts, try to improve the child's condition. When some mothers realised that this would not improve their children's condition, they reported that they sometimes became angry. This could involve anger at a particular cause or a person. Mothers in the current study reported feelings of anger when they perceived that their children's needs were not met. Vanegas and Abdelrahim (2016), in their review of articles about family support, also found that anger was projected onto specialists, who, according to parents, do not provide sufficient medical assistance to the child (in the case of doctors) or do not educate their children well enough (in the case of teachers). They found that the source of anger could be irritation caused by the lack of adequate assistance from specialists and service providers, or fatigue by parents not being able to access services. Vanegas and Abdelrahim (2016) reviewed 103 articles published in the United States in order to obtain an overview of family support and support to families of children with disabilities. The reviewed articles included a range of disabilities, and 22 of them focused mainly on ASD. The studies they reviewed included many family members, including children with a range of disabilities, mothers, parents, grandparents, fathers and siblings. The review highlighted the various feelings which families of young children with disabilities experienced and how these could affect them psychologically and physically, as mentioned in the previous paragraph.

In addition, mothers in the current study expressed the view that the social exclusion of their children with ASD could affect their feelings towards them. They reported that their children were often excluded from social activities because they behaved differently, which might contribute to the estrangement of family and friends. Mothers felt that their children have different behaviour from that of typically developing (such as being unable to play with other children, having some tantrums that kept other children away from them, or in many cases, being dependent on their mothers in their self-care). All these behaviours led to exclusion from social activities, which in turn caused emotional responses to mothers' responses. When explaining these responses in the light of the social model (see literature review section 3.2) the lack of structural and government support may result in mothers internalizing this lack of support and attributing their experience of stress. Parents may view their child as 'different' from other children, but the outside society's devaluation of their children may affect the family management effort (Rogers, 2007; Fisher & Goodley, 2007).

Herrema et al. (2017) investigated 120 family members of adults with ASD in the UK about their concerns about their relatives. This study found that the lack of services available for children with ASD could create concerns for family members who felt that they might not be able to meet basic needs and requirements, and that they might need to strive for ASD specific and tailored services essential for their relatives (Herrema et al., 2017). Similar findings were also reported by mothers in the current study, as lack of services for their children with ASD led them to feel angry as their children's basic needs were not met.

The Omani mothers in my study also reported that their children's development had an effect on the way they acted towards their children and influenced their decisions about their education. Mothers' observations about their children's development filtered the way they perceived their children's needs and in turn directed them to think deeply about decisions, for example, which placement would be suitable for their child's needs. Development such as in social skills and mothers' positive/negative feelings would affect their decision about the placement. In this way, then, the children's development contributed to the mothers' responses to decisions about placement for their children.

Hopes and concerns for the future

Mothers in the current study in general were fearful, anxious and worried about the apparently unknown future for their children. This is consistent with a study conducted by Easter Seals in the United States (2010) which also found that the majority of parents of children with different disabilities, including ASD, were concerned about their children's future. Most of the parents who were surveyed in this study of 1,714 parents of children with ASD and different other disabilities in the United States, reported that their main concerns were to do with what would happen to their children with ASD when they, their mothers, were no longer around. This fear may stem from the mothers' concerns about the support available from social services, from extended family members and from the wider community and their lack of confidence in these. (Services will be discussed in section 6.4 and support in section 6.5). Finke et al. (2019) in their study of parental hopes for their children with ASD found that 77.4% of parents of children with ASD in the United States hoped for their children's independence, happiness, skills improvement, and social relationship improvement in the future. Mothers in the current study voiced similar worries and hopes about their children's future. They were fearful about this and hoped that their children would be happy and independent, at least in terms of daily life skills. Their concerns varied in specifics, from having 'real friendships' to having the ability to live and work independently. Such findings are consistent with those of the study conducted by Easter Seals (2010), where parents' concerns were mainly related to the child with ASD not having enough financial support once the parents die and the child not being able to find employment. In the current study, mothers also reported their fears that their children would be dependent on them or their siblings and would not be able to be employed because of their being unable to work.

Mothers in the current study's feelings and perceptions about their children's future were affected by their children's characteristics, varying from being high-functioning to non-verbal, and their children's educational placement and educational prospects. The mothers of children with ASD who went to mainstream schools and who were verbal reported higher expectations for their children's future than other mothers. These findings are in line with research conducted by Arellano et al. (2019), who surveyed 142 mothers of children with ASD in the UK and reported a correlation between the level of the children's education and the level of the mothers' expectations for the future. It seems that academic achievement is seen to be an essential contribution to the future of a child with ASD, in the eyes of mothers. In the current study, mothers whose children with ASD attended mainstream schools or were achieving academically, hoped for their children to gain a degree in a specific field. On the other hand, mothers of children with ASD who were going to special centres hoped that their children would be independent in their main daily life skills, such as getting dressed, going to the toilet and eating. These latter mothers seemed to have concerns about their children's future because they were perceived as perhaps needing long-term care and being dependent on their parents and siblings far into the future. Mothers in this study were also worried about their children's vulnerability and the possibility of their being harmed by others. However, some mothers took the position that they could not make accurate predictions about their children’s future, so they needed to remain open-minded in order to be prepared for the unpredictability of the road ahead. In addition, mothers in this study expressed hope for the development of the services for children with ASD and their families in Oman. They hoped that the current issues to do with support services for children with ASD (discussed in section 6.5) would be resolved and that the services would be developed further to meet needs properly.

Influences on mothers’ emotions

Mothers’ emotions have been discussed in relation to different stages: the diagnosis process, as the child develops, and in terms of their future. Some influences on these emotions have been mentioned in this discussion, for example, the lack of information, the child’s characteristics, social exclusion and the child’s educational placement. In this section, two further influences are identified and discussed: the Omani community attitude towards children with ASD and the availability of support.

It seems that the Omani **community’s attitude** towards children with ASD is generated by a lack of public awareness about the condition, the nature of ASD as a hidden disability and the marginalization of children with ASD by many public authorities. These aspects seemed to directly affect the mothers in this study. Mothers frequently reported encountering negative attitudes and social stigma from extended family members and the wider community. Research in this area has identified the effects of social stigma on parents and families of children with ASD (for example, Gobrial, 2018; Kinnear et al., 2016) as being a sense of an increased burden of responsibility and increased anxiety and sadness about the affected child’s condition. Parents in these studies reported that the difficulty of dealing with social stigma, such as the isolation and exclusion, played a strong role in making the lives of parents raising a child with ASD challenging. This study connects with the findings of Brett (2002), who suggested that when the wider public views a person with ASD, all that they see is a disabled person who has failed to fit into their community and therefore does not belong in a normal social setting because they cannot adapt to such an environment. Accordingly, the community focuses on what children are not able to do because of their disability. On this basis, caring for a child with ASD puts a burden on the family that is caused by the community. This finding is echoed by Dowling and Dolan's (2001, p.22) statement that ‘‘the child does not handicap the family – society does”. This is may be attributed to the different models of disability which was explained in the literature review (see section 3.2) in which the society disable the children and their families (Ryan & Runsiwck-Cole 2008; Rogers, 2007).

Furthermore, shaming and criticism from other people often played a role in posing challenges to the mothers of children with ASD in the current study. Some mothers and some of their extended families in this study perceived ASD as the work of ‘evil spirits’, which made the mothers hide the condition from the community or their extended family. In turn, this made many of the mothers feel isolated. This is consistent with the findings of previous research by Wong et al. (2016), who studied the negative outcomes among parents of children with ASD in Hong Kong and the things which affected their well-being. This study was not specifically about evil spirits, but more about the challenges parents of children with ASD face.

For mothers in the current study, they perceived there to be a lack of support in terms of information and of medical, psychological and educational services for their children with ASD. Support, in terms of family support or lack of it, also seemed to influence their emotions, which will be discussed in detail below (section 6.5). The work of Gabel (2018) highlighted that mothers who are often subjects of scrutiny by the public. The society disables people by employing measures for accessing public spaces. “The social interpretation of disability, often referred to as the social model of disability focuses on the social, economic, and political barriers that disable individuals with devalued embodied differences (for example, impairments, medical conditions) and prevent them from full inclusion in all aspects of society” (Gabel, 2018 p. 553-554).

Mothers in this study reported little in the way of the positives of raising a child with ASD. Other researchers have examined the benefits of the existence of a child with ASD in a family and found that there could be a greater sense of family cohesion resulting from caring for the affected child (Smith et al., 2015; Ekas et al., 2016). However, the only positive feelings that were reported by any mothers in this study were related to the levels of support that they received. This positive feeling was also one of Al Bloushi's (2019) findings about improving social support networks. In her thesis, some mothers indicated that caring for a child with a Cerebral Palsy had a positive impact in terms of building new social support networks that included mothers caring for disabled children and different service providers. For example, they reflected on the positive impact which led her to become more extroverted as they developed social support group for disabled children to share their experiences. As such, it may be concluded that the availability and accessibility of support may influence the feelings of mothers about their children's condition.

In conclusion, mothers of children with ASD in Oman in this study passed through a series of feelings upon the diagnosis of their children with ASD, including feelings of shock, denial and sadness, as well as emotions beyond the diagnosis stage. The individual child's characteristics, family and community support and the availability of services in Oman seemed to affect the intensity of the mothers' responses to their child's condition. Different stressors affected the lives of Omani mothers of children with ASD, such as fears and concerns for the future, constant concern and social stigma from their extended family and community. These difficulties and stresses varied from mother to mother according to the severity of the child's condition, and because different mothers had different levels of support and services available to them.

6.2.2 Roles and responsibilities of mothers

In this section, I explore the finding from the current study that some mothers had developed a number of specific roles and responsibilities in order to support their children's skills and education. There were six roles: 1) researcher (to find out about the condition); 2) investigator (seeking diagnosis); 3) fighter for resources (developing a personalized plan for their children); 4) primary caregiver; 5) decision maker (attempting to access social and educational services); and 6) negotiator (being involved in their child's educational plan and accepting their child with ASD). It can be noted that mothers largely operate within a medicalised model of disability (see literature review section 3.2) as their interactions are mainly with medical, which will be explored in more details in the coming sections.

Mothers as researchers

The concept of ASD for many of the mothers in the current study was new and unfamiliar, so they attempted to understand their child's condition. They reported that they had to explore the meaning of ASD in different places, such as books, the internet or workshops. This is consistent with the findings of Mackintosh, Myers and Goin-Kochel (2005) who carried out a study in six countries: the USA, Canada, Australia, New Zealand, England and Ireland. 498 parents completed their web-based questionnaires about the sources they used for information about ASD and reported that they attended workshops, conferences and ASD support groups, even though these cost money for registration and sometimes for hotels and travel. Mothers in my study also used a range of strategies to seek information about relevant therapies. The mothers reported that they were not given guidance from any professionals about how to proceed with therapy options, resulting in their attempting to educate themselves, for example, through searching the Internet. Carlsson, et al. (2016) conducted a study in Sweden, interviewing parents of children with ASD about their early experiences. These parents, unlike those in my study, reported receiving information from authorities. However, they said that they received a lot of information all at once that they could not formulate, because they were overwhelmed by the sudden overload. In my study, some mothers also reported that they became overwhelmed by the huge amount of information that they located in their search for suitable therapies and thus in their decision-making processes for how to proceed with supporting their child.

Mothers as investigators

One of the experiences of mothers was their role in seeking a diagnosis for their children with ASD that would convince them of their child's condition. This could be the result of the birth of a child that did not meet their expectations. In Rogers' study (2011), if the normative expectation of celebrating the child's birth was not met, mothers or parents in general were obliged to change their daily life and routines. Mothers in the current study also reported that they had to seek another opinion that would lead them to be convinced that their children needed more support than a typically developing child would need. For many mothers in the current study this understanding was a turning point in their lives, as they wanted to help their children as much as possible. Many mothers, even from middle income families, went abroad for a second opinion or for 'treatment' (as they reported). They said that the reason for seeking a diagnosis abroad was related to the limited services available in Oman (see section 6.2.1 about availability) and to the lack of trust in professionals in Oman, because, according to these mothers, professionals failed to provide a diagnosis and information regarding their children's condition. According to these mothers, professionals in countries abroad were more specialised in topics relevant to their children with ASD, while in Oman ASD is a recent topic that has not yet been experienced by professionals.

Mothers as fighters

Some mothers of children with ASD experienced excessive restrictions on personal freedom and time due to the over-dependence of their children, and they had very low self-esteem, as they believed that they did not fulfill their maternal role well enough (Boshoff et al., 2016). For this reason, some noted that they needed to develop a personalised learning plan for their children with ASD that focused on the child's specific needs, in order to reduce this over-independence. Rogers (2007) also stated what is called "care work", (p. 156) which included the day-to-day activities and that their caring role might go beyond ordinary parenting activities.

As part of the plan, mothers in this study felt that sharing caregiving responsibility between mothers and fathers and other family members was considered essential in order to reduce their stress. Nahal et. al's study (2017) in Palestine found that childcare was regarded as a shared responsibility. They reported that mothers and fathers both contribute to supporting the family unit and part of their responsibility is to care for their children, especially those with special needs. Mothers' role was to invite fathers to share responsibilities in taking care of their children with ASD.

The mothers in this study expressed hopes in their stories for development and progress in their children's condition. Regarding the experience of finding educational placements, mothers reported that they felt a need to make their expectations for their child more realistic and suitable for the child's condition, so that they could succeed. For example, in order to achieve good results in terms of life skills, mothers wanted to set up a plan that was realistic given the child's characteristics. Mothers also tried to gather information about each stage of the condition in order to make informed decisions regarding a placement that would help maximise the child's potential.

Mothers as primary caregivers

Though sharing responsibilities has been considered important by many Omani mothers in this study, they reported themselves to be the primary caregivers for their children in general and for children with ASD in particular. This is because of the responsibilities that a mother is expected to take on according to the Omani societal perspective. A mother who is taking care of her children believes in their children's potential and that one day they will achieve success in life or be independent. This belief seemed to support mothers in the process of accepting their children's ASD. and, according to some, helped them achieve 'acceptance and satisfaction' (Athari, I), which in turn helped them to develop the patience needed to support their children. This is in line with Nahal et al.'s study (2017), which found that Palestinian mothers perceived caring for a sick or disabled child to be a natural extension of their mothering role. This sense of responsibility seemed to influence the mothers' decisions and choices for their children with ASD, compelling them to do their best in terms of their children’s care and education.

In addition, mothers of children with ASD, in the current study, are more heavily involved than fathers in doing things to meet the needs of their children, such as choosing interventions, and educational plans that they think might meet the children’s needs; the fathers are more typically responsible for providing a source of income. This notion fits the Omani case well, as Omani mothers tend to be the primary caregivers for their children, especially for children with ASD. There is a belief in the Omani community that raising a healthy, well-educated child is more the responsibility of the mother than the father in a family. In addition, when encountering the public, explanations about the child’s condition and the causes of the disability were more frequently associated with the mothers in this study than the fathers.

Mothers as decision makers

Because of the nature of ASD, mothers in the current study reported that they had to decide for their children what educational opportunities they should have. In the current study, the mothers’ placement seeking process began with seeking information about the availability of services (see section 6.4.1) to inform their choices and actions related to their children’s education. They reported that the placements had to meet their children’s needs. In order for the process to be effective, the professionals in school or a centre in this study did not share their views about the children’s needs with mothers, which, in turn, had an impact on the placement decisions. Delmolino and Harris (2012), in their study in United States, found that professionals could assist parents in their decisions for their children, and this assistance was found to be supportive, which is different than what has been found in the current study. The current study reported that mothers found that discussion with professionals about their children’s potential, as well as the expectations regarding the focus of education, eased the ability to reach a decision about education that satisfied mothers. Many believed that it was up to them to negotiate their children’s placement and try to enroll them in the best educational setting possible to meet the child’s needs, because they believed that they, as mothers, knew better than professionals. Mothers in the current study also reported that they did not finish this negotiation process at the stage of enrollment, saying that they needed to follow up on professionals’ work through continuous communication with them. They stated that they needed to actively engage in their children’s education, explore possibilities and attend meetings with other professionals and institutions. Hoover-Dempsey et al. (2005) conducted a study which showed that the extent to which mothers became involved was limited only by the amount of time and energy that they were able to dedicate. Similarly, the current study found that mothers reported dedicating time to visiting schools, listening to professionals and investigating their choices before making decisions.

In the current study, mothers attempted to ensure that their children had access to social and educational services. They reported that their responsibilities included choosing schools and generally managing the educational placement process. Mothers also reported that their responsibilities included attending rehabilitation and medical appointments, providing home therapy, exploring religious and herbal treatments, seeking information, navigating organizations that provide services for children, praying for a miracle to help their children, and promoting their children’s social participation. The notion of responsibility and constantly striving to meet their children’s needs has also been reported in a previous study (McDonald, 2010). McDonald’s (2010) in-depth case studies investigated six families in Australia, looking at how they dealt with the education of a child with ASD over time. Parents in this study strove to find services for their children with ASD. The mothers had the major responsibility for the education of their child with ASD, while the fathers supported the family financially (McDonald, 2010). The study also found that the majority of educational decisions were taken by the mothers who dealt with the situation on an ongoing basis (McDonald, 2010). Consistent with the parents in McDonald’s study (2010), mothers in the current study were keen to approach a wide range of services for their children with ASD and described a need for a high level of commitment on their own part in finding the right support for their children’s development. They also stated that there was a need to make them as ‘normal’ as possible, despite the possible social, financial and educational challenges of doing so, this sense of responsibility represented a notion of ‘power’ for mothers, as they perceived themselves to be the first caregivers (as mentioned in the previous section) for their children’s needs, be they emotional, practical or financial.

Mothers in the current study reported a persistent lack of academic progress or understanding of the academic and social needs of their children and the nature of their disability. They also reported using their own strategies to improvise their own educational programmes based on their past experience, their confidence in certain strategies, the age of the child and the financial situation. This was found to be in line with the findings of Samadi and McConkey (2018), in their study of 112 parents of children with ASD in Iran. They found that some mothers experienced a constant lack of educational adaptation in mainstream school environments and decided to place their children in a special school, thinking that this would support their children with ASD better. Similarly, mothers in the current study reported that lack of educational understanding, and the fact that adaption to meet their children’s needs had to influence the decision-making process for their education.

Mothers as negotiators

Mothers in this study reported that their involvement in their children’s education, in ways such as finding a placement, included stressful feelings regarding institutions. Consequently, they talked about a need to fight as much as they could to make the system (whether a special centre or mainstream school) work for their child in order to meet their needs. In order to do this, these mothers reported a compulsion to learn as much as they could about all aspects of their children’s condition and learn strategies to obtain better outcomes, as well as to educate others, such as immediate and extended family members, about valuing their children with ASD. As was mentioned in the literature review, children with disabilities have typically been educated in full-time special education settings in Oman where it is considered that their needs can be met. However, there has been a movement towards parents wanting their children with disabilities to be included in mainstream education (Starr et al., 2006). The current study revealed the role of mothers in the placement process to be mainly determined by their beliefs and concerns about their child’s abilities (stemmed from the medical model as the problem lies within the child). These have been found to guide mothers’ actions and choices throughout the placement process. For example, some mothers focused more on their child's condition and the severity of ASD, while for other mothers their children’s condition was not a constraint stopping them from choosing mainstream education.

6.3 Influences on educational choices and decisions

Finding an educational placement for a child with ASD was seen by mothers in this current study to be a difficult process because of various influences, including the difficulty of reconciling the hoped-for placement and the actually attainable one (Rogers, 2007; Rizvi, 2018). This section expands the discussion of this topic, adding to the influences affecting the placement finding process and examining the interactions between these influences. In this study I sought to understand the influences that might affect the parents’ decisions for their children with ASD, as the act of choosing has been found to be a challenging and complex activity for mothers, because the choice of educational setting needs to suit the child with ASD. Mothers described some influences affecting the process of finding educational placements, their decisions or choices for a place for their children with ASD, and these are summarised in figure (6.1). The branches of the diagram scaffold the discussion which follows.

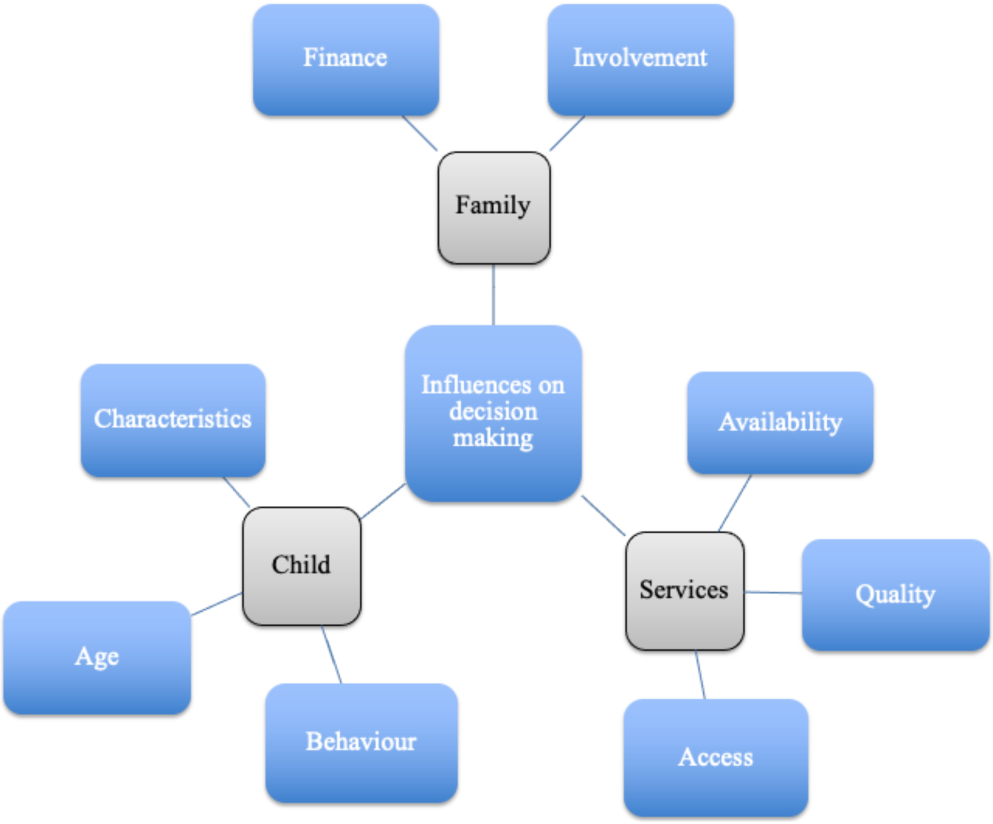


Figure 6.1. Influences on decision making

6.3.1 Family

The first influence on choices and decisions is related to family circumstances, such as the source of income. Many mothers reported that their decisions and choices were affected by whether they were able to fund their children's education or not. They had to consider their financial ability to pay the fees of centres or schools.

Sung et al. (2017) noted that parents are increasingly aware that raising their children with ASD is expensive and more difficult than raising typical developing children. Some mothers believe the **financial influences** affected their decision-making process, because they think that successfully educating their children with ASD will ultimately reduce the pressure on their families for the rest of their lives. After early intervention, parents often desperately hunt for mainstream schools that will provide the appropriate educational experiences and enough dedication to their children (Strain, 2017). Mothers in this current study generally preferred mainstream schools over special centres, as mentioned earlier; however, they were reluctant to allow their children with ASD to go to mainstream schools, their concern being that they might not be accepted. They were afraid that their children in such an environment might be subjected to constant negative treatment or bullying. During enrolment, mothers found that their children were often perceived as a burden by the school that would put more pressure on staff and other students. This would lead mothers to think of either private mainstream schools or centres in order to find a place that meet their children’s needs and in Oman these are very expensive.

Another influence on choices is the extent of the mothers’ involvement in the plans for their children in their child’s current school or a centre. Mothers’ perceptions of the effects of the educational placement on the child’s academic and social development were a further factor. Some mothers reported that the benefit they were seeking from education was more to speed up their children’s social development, while for other mothers their academic education was a greater concern. Their perception about the benefits their children may gain, influenced mothers’ choices and decisions. They reported that the special centre settings were limiting their children’s academic development. This was also reported by Swick and Hooks (2005) in their study about parents, although mothers also expressed concerns about their child’s emotional well-being and fear of social rejection.

6.3.2 Child

The education of children with ASD could be approached by considering first the child’s characteristics, especially they generally have serious issues interacting with the outside world. The characteristics, age and behaviour of such children are another influence that my study found impacted mothers’ decisions. A child with ASD may struggle with making connections with family and society because of their impairment and they tend not to be able to connect in the same way as children with other disabilities (Bradshaw et al., 2018). The mental development of a child with ASD is not just delayed or impaired; it is distorted, since the mental functions of such a child develop not as a consequence of social interaction and solving real-life problems, but to a large extent from neuro-stimulation. This is a mean of restricting rather than developing interaction with the environment and other people (Bradshaw et al., 2018). Mothers in this study described difficulty in enrolling their children with ASD in mainstream settings because of their inability to cope in such settings. In addition, these mothers believed that their children were often viewed at school as pupils who need additional resources, so taking on children with ASD without the support and resources required was something that schools were not keen to do. Mothers found that some schools immediately rejected children with ASD or would need a specific diagnosis and external financial support before accepting the child. When mothers in this study finally got a place for their children with ASD in mainstream schools, these schools did not meet their children's needs. They reported that in mainstream schools, whether public or private, there were many different views on inclusion that affected the type and intensity of support that their children would receive. Some mothers often had to negotiate and argue about acceptable strategies of education that would meet the needs of their children with disabilities (Rogers, 2007). Many children who were included in mainstream schools often experience practical, intellectuation and emotional exclusion. Depending on the success of the inclusive culture and practice of the school, the participation of mothers in the school or centre's practice was found to be effective in meeting the needs of their children. According to Rodgers et al. (2008), parents' involvement in their children's education is encouraged to support inclusive education (or mainstream setting) for children with SEN.

Children with ASD are diverse, according to Wall (2010), therefore the educational setting is likely to vary from one child to another, and for each child will vary from one point of time to another. Mothers found that the effectiveness of the educational setting for their children with ASD needed to be recognized and planned, as well as there being a need for a continuous discussion and involvement between parents and professionals. The mothers' act of choosing whether or not the child might be placed in mainstream schools or special centres also depended on the child’s characteristics. Some mothers wanted their children to be educated in a natural environment, just as their other typically developing children were educated. When parents consider their choice for their child’s education, they consider their desire for their child to live as normal life as possible and believe that special education settings might limit their child’s academic and social development. This was similarly reported by Swick and Hooks (2005). However, there were other parents who expressed concerns and doubts about whether mainstream schools would contribute to their child’s development and whether their child would be able to cope in such a setting. It was found that mothers were diverse in their approaches to the choices for their child, depending on their children’s characteristics and their ability to be independent or not. These findings are consistent with those of Flewitt and Nind’s research (2007), highlighting parent’s decisions to adopt and choose a setting that enables their child to participate in mainstream educations while still receiving specialised services. The child’s age also influences the mothers’ choices as services are more available for younger children, but there is more difficulty in finding services for older children. Mothers in the current study reported that age affected their decisions in finding places for their children as they grew up.

Mothers indicated that they needed to accept their children as they are. Though feelings of stress were reported by many mothers in this study, they still had the belief that their children had unique characteristics that they needed to consider in order to promote their learning as much as possible. Mothers in this study indicated that they had to undertake specific actions in order to gain access to the educational environment that would support their children’s development and that would be tailored to their needs. Their actions were basically related to obtaining information about their child’s current abilities, gaining any available resources that might meet their child’s needs and accessing all services possible. However, this approach is considered to be one of ‘trial and error’ approach (Hoogsteen & Woodgate, 2010). This is the way that mothers in the current study negotiated the options that they felt would be suitable for their child and would satisfy them as mothers.

6.3.3 Services

One of the influences that was reported by mothers was associated to their experiences with previous or current services, such as schools or centres. The work of Rizvi (2017) resembles similar findings from the current study. She investigated the understanding of five immigrant Pakistani mothers of their children's disability from an educational perspective, highlighting their maternal role to support the development of their children's condition. The findings of Rizvi's research highlight the understanding of disability and the schooling experience which reflects the different social constructs of mothers at different times. During early years, mothers understood disability in pathological terms influenced by professional medical interaction, as children grow older, educational practitioners were more involved. Similarly, this is happened to Omani mothers' when experiencing schools' decisions, and this is not limited to Omani mother nor to South Asian mothers (Rizvi, 2017).

The findings of this study showed that mothers were unable to fully control their placement decisions and that there was a conflict between their own preferences and those of the education system. Many of the mothers would be keen for mainstream systems to take their children; however, such systems would not accept them, as they would be considered unable to cope in mainstream schools with typically growing children. The mothers' emotions and tensions would be increased because of the uncertainty of their hoped-for placements being achievable. The work of Rizvi (2018) also suggested that mothers accepted placement decisions from 'expert opinion' and hoped for more inclusive settings as this would secure better provision for their children in the future.

Some mothers in the current study described situations of encountering difficulty in mainstream education settings. This finding was also reported by Harrison et al. (2016), who found that this happens when a child goes through traumatic events, such as the child refusing to go to school or being excluded or suspended. Mothers reported that if staff, the headteacher in particular, do not have a firm commitment to implementing the methods that would meet the child’s needs, to allocating the required resources and undertaking the necessary special evidence-based training to learn about ASD, a child with ASD in a mainstream environment quickly deteriorates and is blamed for any problems that arise. Van Herwegen et al. (2018) stated that most parents believed that a lack of appropriate practices in school-based education over time has directly led to problems for children with ASD. Some mothers in the current study reported that they could not find a mainstream school that could provide adequate education for children with ASD, which in turn led them to consider special education, even though they felt that their children deserved to be in a mainstream setting.

Mothers in this study found that complementing the education of their children with ASD themselves was another responsibility that they could undertake to maximize the educational progress of their children, though it contributed more difficulty to the mothers’ lives. This echoed the findings of Petrina et al. (2016). If parents worked determinedly in finding an educational environment in a suitable school or centre, the children were often reported to be making progress in their development. In the present study, some mothers reported completely withdrawing their children from mainstream schools to find special schools or centres for them in order to protect the mental health and wellbeing of their children. Some mothers preferred to homeschool their children with ASD. Mothers also found that support from social services for their children’s education could significantly increase the level of education that their child could access and play a role in reducing the burden on the mother and the whole family.

Mothers in the current study highlighted the importance of the social factor in the placement process. They felt as though they were fighting for their child’s rights, expressing concerns and hoping for better support from professionals and relying on social support in the placement process. Mothers should be acknowledged as key decision-makers in the process of finding educational placements for their children, and the choice of educational provision strongly influences the mother’s wellbeing as well as the child’s. The current study has themes in common with the findings of other studies mentioned above and has shed light on the issue of mothers finding educational placements for children with ASD in Oman.

6.4 Services (availability, quality and access)

In this section, though the focus of the current study is on education, points in relation to healthcare and social services will be mentioned as well as educational services. In this study, mothers' decision-making was influenced by the **availability, the quality and the access to services (see 6.3 above)**. It found that mothers accessing services for their children with ASD was a complex process (see Chapter 5, section 5.5.6). There were a number of issues. The main issue was to do with accessing information regarding the available services for children with ASD. Mothers also expressed dissatisfaction with the limited scope of the services and support available, including the absence of any support or services for the mothers themselves. In addition, some mothers were not able to access services and support from public authorities. Some also expressed dissatisfaction with the way that they were treated by public and private agencies when applying for schools. Others were dissatisfied with the quality of provision, for example, the competence of specialists and practitioners, in public or private institutions (schools/centres).

Regarding education, mothers expressed disappointment, and sometimes stress, about a number of aspects. They were disappointed about how the placement for children with ASD was decided. Mothers had to explore alternatives and evaluate educational placements for their children with ASD on their own. There were no professionals to support them in this search and decision. They often started out with one preference, for example for a mainstream school either private or public, but then later realized that what they considered would be suitable at the beginning of their search was not necessarily realistic. Some mothers in the current study described a situation of feeling left without the ability to make decisions by themselves as they were not familiar with the condition of ASD and the available services, which resulted in negative feelings such as disappointment and regret. Mothers reported disappointment in the limited availability of placement options within the Omani community, and in the quality of provision in institutions.

Each of the aspects of availability, quality and access will be discussed in turn below.

6.4.1 Availability

As it was mentioned in chapter 2 section 2.5 there were some services available for children with different disabilities in Oman. Al Bloushi (2019) provided a brief summary of the services provided in Oman for children with different disabilities such as issuing a card to each individual with disabilities, whether adults or children and maintaining a registry. The card works as an authorisation for them to obtain facilities at different governmental and non-governmental agencies. In addition, the ministry supervises 23 rehabilitation centres and nine centres that belong to the Omani Association of Handicapped. The ministry also supervises other non-governmental associations and centres that provide educational and rehabilitation services to disabled persons (MOSD, 2018). The community-based rehabilitation centres and the Omani Association of Handicapped Children centres are day care centres that provide rehabilitation services, social and psychological services and health care services (MOSD, 2018).

However, mothers in this study reported that the services and the places that would accept their children were limited, so there was little available for them to consider in order to make their decisions (see Chapter 5, section 5.5.6). Availability, however, was not just about the existence of educational placements; it was also about the availability of these placements to children with ASD. There were few private centres and very limited places in public centres that would include children with different disabilities, and which might accept children with ASD under very limited conditions, such as the children being able to care for themself. The fulfillment of the desire of many mothers to place their children in mainstream schools also seemed to depend on the school's acceptance of the child. In many cases in the current study, mothers reported that children were rejected without the school attempting to assess the child's potential. Some mothers reported that they had to stop mentioning their child's condition to the schools. Their previous belief about reporting the child's condition to the school had been in order for the school to consider the child's condition and to support them accordingly. However, they found that this simply led to the child being rejected from the school instead. Thus, whilst, to some extent, a range of educational placements existed, they were not 'available' to children with ASD.

Many mothers in the current study claimed that their children with ASD had not received services before the age of four. They also reported that no services had been organized specifically to support mothers. This may suggest that the significant benefits of early intervention services for children with ASD and their mothers have not been yet realised by the stakeholders and decision-makers in Oman, and that these may need to be considered when planning interventions and developing programmes for children with ASD. Even when placements were available, because of the lack of information received from authorities, mothers found it difficult to consider the appropriateness of a certain setting even if it was the only one available in their region for their children with ASD. Al Bloushi (2019) reported that parents expressed dissatisfaction about the services provided for the children with disabilities, dissatisfaction with the way of communicating the diagnosis of their child's impairment; inadequate information provision regarding the child's impairment; lack of information on the child's care management and the services available to help with daily living and the child's future development. These challenges were also reported by mothers in the current study.

Mothers found information, for example about placement possibilities, and other types of support, for example emotional support, to be unavailable from formal support structures, such as local authorities and professionals, and thus reported a need to access social resources, such as family and community, to provide such information and support (Rizvi, 2017). The use of social support was found to be a strategy used by 16 mothers in studies such as that by Lutz et al. (2012) in the United States. In Oman, because of the absence of formal support, mothers seemed to depend on informal support. This will be discussed further in (6.5) below.

According to the mothers in the current study, although the Omani government has disability legislation and provisions for children with disabilities (see Chapter 1), there is still a significant shortage in the services provided for children with ASD and their families: there were few choices or opportunities regarding services and support available for the majority of mothers in this study.

6.4.2 Quality

This study presents mothers' perceptions of the services and of how well they would meet their children's needs. The current study found that mothers were dissatisfied with the healthcare services, social services and educational services they received from local authorities. This might stem from the professionals in Oman having a lack of awareness of ASD, as was reported by Al-Farsi et al. (2016) who explored the awareness of ASD among health workers in Oman.

Zuna et al. (2016) conducted a descriptive statistics study in the United States to examine parental perceptions and the satisfaction of families with the available services for children with ASD and other disabilities. The results showed that the parents participating in the study were generally satisfied with the services received. Service costs, parent-professional partnerships and the general quality of service, however, were considered insufficient for the parents' needs. Parents also stressed the need for early intervention, family counselling and public information services. According to the mothers in the current study, the services for children with ASD in Oman, do not meet the requirements needed for their children Mothers in the current study also reported that teachers or specialists lacked the competence to deal with their child with ASD and stated that the quality of service was a factor in deciding on a school/centre.

Parsons et al. (2009), in their study about parents' satisfaction with educational provisions for children with SEN or disabilities, concluded that parents of children with ASD in the UK expressed dissatisfaction with the information provided for them when they came to choosing a school. Their findings suggested that such parents require extensive information in order to be assured of the adequacy of the available placements (Parsons et al., 2009). Similarly, when mothers in this present study found the information, they considered necessary for making their decision, it reduced their anxiety and frustration.

The mothers in the current study also reported that they encountered unqualified institutions that were not able to meet children’s needs. They also said that they were disappointed with the ability of staff, teachers and other professionals in the educational system in Oman as they seemed, to lack training and knowledge about ASD. In addition, both healthcare and educational professionals in Oman, mothers stated, were not able to provide adequate resources to support and enhance their children’s development. Such findings have also been reported in other studies in the Middle East, such as that of Gobrial (2018) who conducted a study with 14 mothers of children with ASD in Egypt. This study found that the “inadequate provision of adequate education, health care and other resources constituted the main issue in relation to ASD in Egypt” (Gobrial, 2018: p.7). Building an effective and urge the parents to seek assistance and raise public awareness of disability become essential (Rogers, 2011). This can be done through reinforcing trust between parents and professionals and institutions through regular meetings.

With regards to quality, some mothers in the current study said that some particular aspects needed to be considered in choosing an educational environment; these were understanding, awareness and ability of teachers or specialists in ASD and the emotional, social and academic wellbeing of the children with ASD. Bolourian et al. (2019) found that parents in their study also paid attention to the self-awareness shown by staff working with children with ASD, seeing what their skills were (if any). Parents in Bolourian et al.’s study argued that this kind of self-awareness was what qualified staff to be part of a team (a community of practitioners) to include students and meet the learning needs of children with ASD. Parents in Lord et al.’s study (2018) in the United States found that when teachers do not uphold the school’s acceptance of children with ASD, the situation can deteriorate. Through their experiences, some mothers in the current study explained that mainstream school environments could be challenging for their children. As Lord et al. (2018) noted, a mainstream school experience was preferred by many parents for its combination of formal education with various activities to ensure that all children’s educational progress and emotional wellbeing are catered for. However, Lord et al. (2018) found that the quality and quantity of the activities that could benefit children with ASD were directly influenced by the teachers’ acceptance of these children, as well as by the individual characteristics of the children. In the best cases, they noted, schools work with families to integrate additional programmes into the educational programmes of children with ASD so that they could develop in an optimal way. Mothers in the current study believed that such services (either educational or other) often lacked quality, which in turn affected the mothers’ decisions about their children’s education. Some mothers chose to look for alternatives and other services for their children, such as taking them abroad or finding another school or centre (see Chapter 5, section 5.5.6)

There were mothers in this study who preferred special centres, believing that they would meet their children’s needs better than a mainstream school would. They doubted that mainstream schools would suit their children’s needs and they felt that the schools did not have the ability, required equipment or physical setting to support the children. These mothers focused instead on choosing special centres that were more tailored to meeting the special needs of their children.

Not all children could thrive in mainstream schools, as noted by some mothers in the current study who thought that their children might learn better in schools or centres for children with special needs. A study of cases of childhood paralysis in South Africa (Lee et al., 2016) reflected this notion, as children showed academic consistency and general improvement in their self-esteem in special centres. However, there is always a tendency on the part of the parents to choose a mainstream school for their children, regardless of their potential, because they want to offer them a ‘normal’ childhood and be generally optimistic about their future. They consider special schools or centres to offer limited development for their children with ASD. This was also reported by Jenkinson (1998), who looked at the perceptions of about 198 parents in Australia of the choice of education for students with disabilities. The majority of these parents expressed satisfaction with the current school settings. However, it was reported (Jenkinson, 1998) that they moved their children from mainstream schools to special schools for secondary education in order to ensure that the curriculum focused on the child's independence and life skills; this played an important role in parents' decisions. Similar study about parent satisfaction with their child's current school setting was undertaken by Parsons et al. (2009). 125 UK parents of children with and without ASD participated in an online survey about educational provision across mainstream and special schools (Parsons et al., 2009). The views of parents in both groups were positive about provision and improvements. According to Parsons et al. (2009), the majority of parents were mostly satisfied with their child's current educational provision, although there were concerns about transitions between and beyond schools. Therefore, good quality of services seemed to be essential to increase satisfaction among parents of children with ASD.

6.4.3 Access

In addition to the availability and quality of services, access to healthcare, educational and social services was found to be an issue in the current study. Key barriers for mothers of children with ASD were access to services generally, access to information (about ASD and about placements), to mainstream schools, to professionals and to decision making about services. In addition, there were barriers to access (or influences on access) such as geographical (urban/rural), income/socioeconomic status, a different culture, a different language, a different background to the service providers, lack of information (relating to availability) and unclear policy regarding access to education.

In the current study, mothers reported that they did not have equal access to services and were dissatisfied with this. Mothers who lived in the capital city stated that they had access to more services, though they considered them insufficient, than mothers who lived outside the capital city. According to Profanter (2009), having a child with ASD, being financially challenged or residing in a rural area doubles the disadvantage and adds barriers to the accessing of support services. Al-Farsi et al. (2012) investigated the views of careers of children with ASD in Oman about the available medical and rehabilitation services for them in the capital, Muscat. Al-Farsi et al. (2012) found that higher-income carers were more likely than those with low-incomes to have access to educational psychologists, occupational therapists, speech therapists and teachers for special needs. However, although they reported some benefits from these services, carers were generally dissatisfied with access to the overall services (Al-Farsi et al., 2012). The current study did not gather information regarding income.

A study conducted by Boshoff et al. (2016) in Australia found that parents described barriers in their ability to advocate for their children, such as having a lower socioeconomic status, a different culture, a different language and a different background to the service providers. All these made it hard for parents of children with ASD to advocate for access to services for them. These barriers, however, were not evident in the current study. One reason for this could be that these barriers were not asked about in this study, but there were questions explicitly about barriers in general in Boshoff et al. (2016).

Access to information about services was an issue for mothers in the current study. This relates to the aspect of availability, as mothers stated that there was a lack of information (as well as a lack of specialists and services). Mothers used a range of diverse strategies to obtain information. To find out about their child's condition, as noted earlier (see section 5.5.2), mothers searched the internet, attended workshops and read books. With regard to information about educational placements, they visited schools, attended school days, talked to professionals and turned to other mothers of children with ASD. Seeking information from other mothers to make informed decisions for their children's placement was also reported in Ludlow et al. (2012). This study, in the East of England, found that parents provided each other with information, advice, ideas and strategies to overcome challenges experienced in the placement-finding process. Ludlow et al. (2012) stressed that parents shared their experiences to provide support for each other that was both valuable and free of judgment.

With regard to educational placement, once this was in place some mothers felt lack of access to information about how their child was doing. This led them to follow up on the professionals' work and try to communicate and be involved in their children's education in order to feel confident with their choice of placement, or see whether a better placement was required. Furthermore, being comfortable and feeling secure within the current placement was a key factor for evaluating the placement decision.

Mothers in this study in Oman experienced difficulties in accessing services. The literature documents that this is not unique to Oman and that many parents in other countries have reported similar difficulties in accessing services for their children with ASD. Gobrial (2018), for example found in a study in Egypt that mothers were unable to access services such as education and healthcare and that this in turn yielded issues for the mothers to deal with. However, such difficulties in access were not found in Pearson and Meadan's study (2018) in the United States. They interviewed 11 mothers and reported positive experiences in accessing services, finding instead that barriers to satisfaction were more related to factors such as limited teacher training and experience (Pearson & Meadan, 2018).

With regard to accessing education, there is no clear policy statement in the Omani educational system suggesting that parents have the right to choose an educational placement for their children with SEN. There is no clear statement that education is compulsory for children with ASD, though the Omani law of SEN states that the government should provide educational services that suit the child's potential (Oman, 63/2008). This might be considered as the main source of conflict between mothers and the system, as they could not find programmes in the educational system which seemed to suit the child's potential or considered their children with ASD. This policy seems to be responsible for the stress and frustration felt by mothers in relation to access to educational services.

In conclusion, this section has discussed mothers' experiences of the availability, quality and access to services for their children with ASD. The current study suggests that mothers of children with ASD in Oman still experience significant barriers and are dissatisfied with the services provided by both public and private institutions. Many mothers sought to access public services first but expressed dissatisfaction with the quality of the services provided. From the mothers' point of view, there were difficulties in accessing what facilities were actually available, the process being hampered by a lack of accessible and relevant information.

6.5 Levels and types of Support

This section will discuss the levels and types of support that mothers of children with ASD in the current study reported that they had, or had not, received. There is an overlap between the levels and the types of support making it difficult to separate them.

6.5.1 Levels of support

Mothers received support from different people and organisations around them. Figure (6.2) portrays these in terms of levels of support.

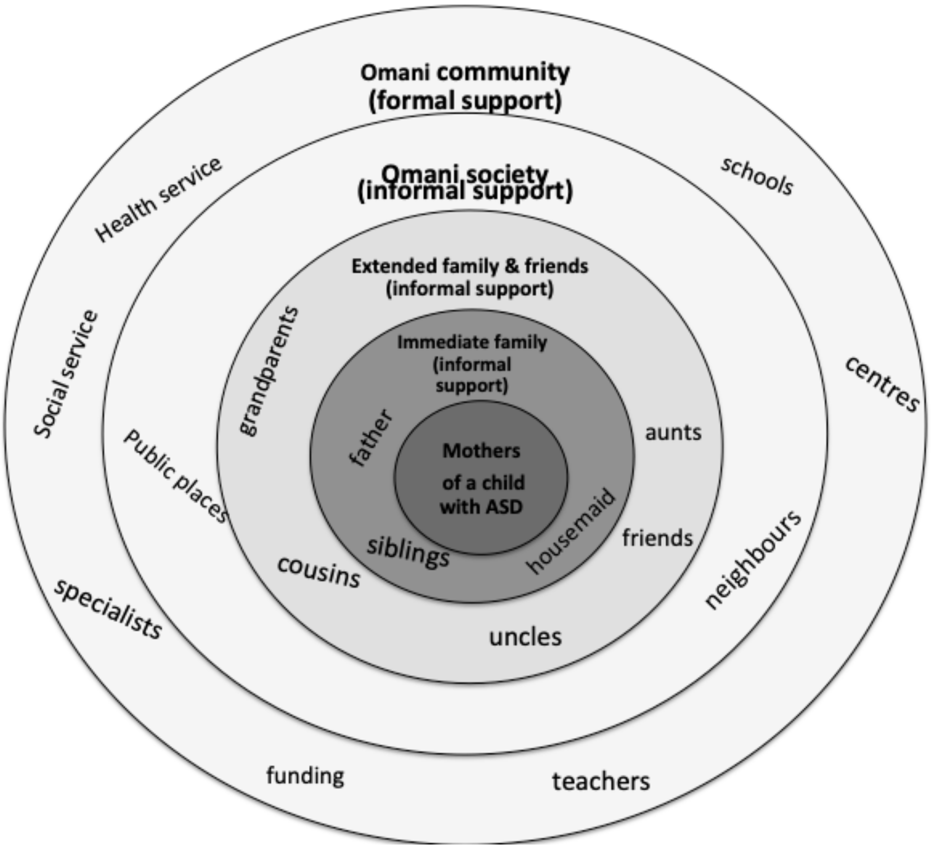


Figure 6.2: Levels of support received by mothers

As seen in figure (6.2), three levels of support were evident: immediate family (including husband/ father, siblings and housemaids); extended family (including grandparents, cousins, uncles and aunts); and community (including institutions and organisations, neighbours, friends, teachers/ professionals). The figure also shows the intensity of support mothers reported receiving. The darker areas indicate that more support was received. It is important to note that this was not the case for all mothers and the figure may not therefore be applicable to all of them. For example, there were some mothers who stated that fathers were not supporting them. Support also took place in different ways. Figure (6.2) also shows a distinction between informal and formal support which will be discussed in section (6.5.2).

Generally, mothers perceived that they gained the most support from their **immediate family** in practical ways, such as taking turns in caring for the child with ASD, and in support for their decisions regarding the child. Mothers reported that they highly valued support from their immediate family members such as husbands, their typically developing children and, in many cases, their housemaid. Many mothers described their husbands to be helpful and supportive, which in many cases made them feel happy and reduced their stress. Hadadian (1994) studied 15 families who had children with developmental delays in Kuwait. He found that mothers who received support from their husbands had better relationships with their children, and that support of family, friends and the surrounding community played a major role in reducing mothers' stress level. Although this study was carried out 25 years ago, some mothers in my study reported similar support from their husbands but felt that their friends and community were less supportive and less accepting of their children. Al Bloushi (2019) in her study with mothers of children with Cerebral Palsy in Oman, reported that they had received societal support and that this was a positive impact on their lives as mothers of children with disabilities.

Children who were provided support were usually older or grown up; their support took the form of physical support in taking care of the children with ASD. It is important to mention that there were mothers who mentioned limited support from their other children. Support of housemaids also tended to take the form of physical support. This level of immediate family support can be described as informal support, which will be discussed in detail in section (6.5.2).

Most of the mothers in my study seemed not to find support from their **extended families or society in general,** both of which they reported as not helpful, or that their help was not given to the extent that they expected. They attributed this lack of support to a lack of awareness about the condition. Society in general was also thought to be unaware of the meaning of ASD and mothers found it difficult to explain their children's condition. In line with some other studies (for example, Al-Farsi et al., 2016; Gobrial, 2018), findings from the current study suggest that, children with ASD appear to be accepted by their immediate family (such as parents and siblings), but are less accepted, or not accepted, by their extended family (such as grandparents, aunts, uncles or cousins) or the extended Omani community. In the light of these findings, the

Omani government and relevant stakeholders may need to plan to involve members from the extended family in supporting children with ASD in order to increase their awareness of the condition.

Mothers in my study said that their children were not accepted by their **extended family** in social gatherings such as those of family, or visiting friends or meeting in public places. In many cases, mothers stated that extended family members and community believed that they, the parents, were responsible for their children having the difficult behaviour of ASD. Ryan (2005) interviewed 23 mothers of children with moderate to severe learning difficulties in England and found that they experienced this: the older their children became, the more they were excluded in public spaces. This was also reported by some mothers in the current study. She also found that mothers experienced a shift in people's response to children with ASD in in public places. This shift changed from tolerance and empathy to fear and avoidance of their children with disability (Ryan, 2005). Similar experiences were reported in the current. However, Al Bloushi (2019) in her literature synthesis explored the informal support that mothers received from their families. According to her, the studies suggested that extended family members were the most common providers of support.

Some individuals with ASD depend solely on their families for support and might eventually face a time when their mothers will be no longer available. Thus, mothers felt that they needed support in taking care of their children with ASD. The findings add to the existing research that documents the importance of support for families of children with ASD in their coping with the stress related to caring for such children. Halstead et al. (2018), for example, surveyed 138 mothers of children with ASD and found that social support had an effect on maternal wellbeing. From mothers' accounts in the current study, it can be seen that in Oman there is a perceived need for improved support services to enable mothers of children with ASD to cope with the difficulties they face, enhance their ability to support their children's development, ease the anxiety and tension within families, and provide better access to services. Mothers in this study emphasized the need for information about accessing services and for financial support in order to meet financial obligations. They also described a need for social and emotional support from different social networks. Mothers in this study reported that they were looking for balance in their lives, which could be generated by support received from families and the wider community. In this regard, the findings of this study, are in line with previous research in Egypt (Gobrial, 2018), which reported insufficiency and inadequacy in services and support for parents of children with ASD.

6.5.2 Types of support

Mothers in the current study depended upon both **informal and formal forms** of support in Oman, as shown in figure (6.2). They received informal support from informal sources such as their spouse and family members, and support from Omani society in general. More formal support was provided by institutions and organizations such as hospitals and schools and/or doctors and teachers/professionals.

First of all, **informal support** is most associated with a supportive husband who would be likely to have a positive impact on the mother's wellbeing. In Oman, in the current study, mothers reported different experiences with their husbands, which is similar to the findings of research by Brobst et al., (2009), where many of the women in the study reported receiving positive support from their husbands. However, there were some mothers in the current study who reported that their husbands completely withdrew from the lives of their children with ASD. The mothers attributed this to the difficult work that their husbands had to do, or to the nature of Omani men, who typically leave the responsibility of childcare to their wives. Even so, many of the mothers in this present study reported receiving full support from their husbands in their life of their child with ASD and in the decisions they made for their children. Mothers also reported their husbands having good relationships with their children with ASD and good levels of involvement in their children's daily care. This study found that a husband can serve as a source of support for mothers and can affect the quality of the family's functioning, which in turn could impact the parents' interaction with each other. Al Bloushi (2019) also found in her literature synthesis for different studies that the greatest amount of support that mothers received appeared to be from their husbands/partners and parents. These studies reported that husbands/partners provided practical, emotional and financial support to the mothers. Another study was conducted by Pruitt et al. (2016), who explored 83 mothers of children with ASD in the United States who were all from different backgrounds. The study investigated the daily wellbeing and parenting experience of these mothers and found that the spouse played an important role in supporting the mother and influenced their wellbeing and quality of life (Pruitt et al., 2016).

It is worth mentioning that, as noted earlier, mothers in the current study also received informal, and often intensive, support from other members of their immediate families, for example, their child's typically developing siblings and the family housemaid. These findings are in contrast to those of Tomeny et al. (2016), who studied 56 typically developing sisters of children with ASD in the United States. They found that the sisters studied were not supporting their mothers with their siblings with ASD. Most mothers in the current study reported receiving intensive support from their immediate family and varying levels of support from other extended family members; this is also considered to be informal support. The support mothers receive from their family members varies from supportive to no support.

Another form of **informal support** that was looked at in this study was societal support, which included social awareness of ASD, how others reacted towards children with ASD and the social services. Most mothers in the current study reported that there was insufficient awareness of ASD, while some mothers felt that awareness of ASD was increasing. Mothers indicated that the lack of awareness of ASD led to a lack of societal support and in many cases reported some degree of not feeling understood by the community when they went out to public places. The findings from this study suggest that the community's perception of ASD in Oman appeared to be unsupportive of mothers or discouraging towards their child's participation in the community. These findings are consistent with those of a study conducted by Al-Farsi et al. (2016) about families caring for children with ASD in Oman. Their study (as mentioned in section 5.2.1) found that most of the parents felt that they could not take their children to public places because their children’s behaviour attracted other people’s attention. Moreover, other studies conducted in Arabic countries have reported that mothers experienced rejection from the public towards their children with ASD. For example, the previously mentioned study by Gobrial (2018) in Egypt, found that mothers felt that the public did not accept their children’s ‘odd’ behaviour and attributed this to bad parenting or to mothers not controlling their children. In this way, some mothers avoided social participation for themselves and their child with ASD and preferred to hide their child, sometimes even from their own extended family (Gobrial, 2018).

It is worth mentioning that a few mothers in the current study felt that there was a small shift occurring in Omani society’s perception of ASD and a growing awareness about the condition that could allow mothers to integrate their children in the community, though there would still be some challenges when they went out with their children to public places. A lack of awareness in the community about ASD, however, meant that support at this level for mothers of children with ASD was perceived as limited

Though **formal support** for families of children with ASD seems not to be prevalent in Oman, the term refers to hospitals (the responsibility of the Ministry of Health), centres (Ministry of Social Development) and schools (Ministry of Education). In this study, mothers saw the support they received from hospitals in a negative way. Many of them failed to obtain a diagnosis and thought that the hospitals they dealt with did not provide enough care or information about the condition. Similarly, Rogers (2007) recommends the importance of support whether it is formal or informal. She suggests that, without the right levels of support and understanding, having a child with a diagnosis a disability may disable the whole family.

The Ministry of Social Development in Oman is responsible for individuals with disabilities, and they provide funding either by paying fees for the centres that children with ASD attend or by issuing a disability card that parents can use to obtain benefits and other services (see Chapter 2). The Ministry of Social Development also provides children with disabilities with a monthly allowance that can help them to pay for their living costs. In addition, the ministry supervises private centres for children with special needs. In terms of centres, mothers found that they could receive some information about the services provided by the Ministry of Social Development; however, many mothers felt that these centres could not meet the needs of their children. In fact, very few mothers reported any good improvement in their children's development because of a centre. Some mothers moved in order to find access to better services for their children with ASD. Like many institutions in Oman, centres follow rules in order to control the use of benefits and some mothers reported that, in many cases, rules had negatively affected the work of the centres. As a consequence, children were negatively affected in an indirect way by these rules. This has been reported in other studies in the Arab world, such as that by Gobrial (2018) in Egypt, by Kheir et al. (2012) in Qatar, by Al-Farsi (2016) in Oman and by Kelly et al., (2016) in the six Gulf countries of Saudi Arabia, Oman, United Arab Emirates, Bahrain, Qatar and Kuwait.

Some mothers in the current study had varied perceptions of schools in Oman and described the Ministry of Education as not concerned with their children. Some teachers were not supportive and did not want children with ASD in their classrooms. In this study, mothers reported that many teachers in schools had little or no knowledge of ASD, and it seemed that they could not provide support for the mothers in their decisions for the placement of their children. Mothers stated that the educational and social service supports are not efficient and that they are forced to rely largely on support within their immediate family. A study conducted by Roffeei et al. (2015) examined the types of social support between parents/carers of children with ASD via Facebook. The findings of this study indicated that most of the support was informational on how to support children with ASD development.

6.6 Summary of chapter six

In this chapter, the main findings were discussed in the light of the aims of this study, the Omani context and the existing literature. The discussion focused on Omani mothers' experiences, perceptions and feelings about their lives with their children with ASD. It also highlighted the mothers' responses towards their children's diagnosis and discussed their perceptions of themselves as the primary caregivers of their children with ASD. It also reported that mothers of such children commented on their experiences when navigating and accessing the services for them. Mothers reported many influences that affected their decisions and choices and the placement process for their children. Support was discussed in two main areas as levels related to mother's immediate and extended family and types of formal and informal support, which were found to overlap.

Chapter 7: Conclusion and Recommendation

7.1 Introduction

This chapter summarizes briefly the key findings of this study along with the main theoretical, methodological and practical contributions in the field of ASD and mothers' experiences. It highlights the implications of the findings and offers some recommendations as to how these can be taken forward in relation to ASD and development of the services for children with ASD and their mothers (mothers, together with their families) in Oman. The chapter then presents the study's strengths and limitations and provides some suggestions for further research. Finally, it concludes with an account of my personal insights and reflections on the research journey.

7.2 Study overview and key findings

This study focused on exploring mothers' experiences, perceptions and feelings about their lives with their children with ASD in Oman. I also sought to explore their experiences and perceptions of choosing the education for their children with ASD in relation to models of disability (section 3.2). I used different methods to collect qualitative data in three phases: story narration by 25 mothers from different places in Oman; semi-structured interviews with 11 of those mothers; and a day with three of the 11 interviewed mothers. These phases provided me with a privileged opportunity to understand and explore Omani mothers' lives with their children with ASD and the educational decisions they made.

Overall, the major findings of the study, as detailed and discussed in the previous two chapters (Chapters 5 and 6), highlighted the emotional responses of mothers of children with ASD towards their children's diagnosis and development, as well as their hopes and concerns about the future. These concerns were associated with some negative emotional responses in relation to their children's future which might cause struggles for them. These emotions emerged from the different understandings of disability. The findings also indicated mothers' experiences of social, health and educational services, with which the mothers reported dissatisfaction as they were insufficient. The findings of this study identified a number of influences which affected the process of mothers choosing the education for their children with ASD, such as availability and accessibility, quality, the child's characteristics and issues related to the family. The study also indicated that mothers reported different kinds of support, either informal from their immediate or extended families, or formal support from the community, in order to help them make informed decisions for their children with ASD. There may be better decision they make, if they receive the appropriate support from professionals.

7.3 Main contributions of the study

The current study sought to address the limited research in Oman on families with children with ASD overall and on mothers in particular. It adds to the body of research conducted in the local area of Oman (e.g. that of Al-Farsi et al., 2011-2016), confirming that ASD has influences and effects on mothers and families of children with ASD. The impact of ASD on education, according to my research, is not present in previous research in Oman about ASD, because most of this relates to a medical perspective (see Chapter 2). With a focus on mothers and on education, the current research is the first study of this kind in Oman, hence it makes a contribution in the sense that it presents a new perspective.

In the following two sections I will address the main contributions to existing knowledge this study makes, focusing in turn on theoretical and methodological contributions.

7.3.1 Theoretical contributions

The current study makes some theoretical contribution to knowledge, not only in the Omani context but also internationally, in the sense that it presents an additional perspective on how to look at the experiences of mothers in their lives with their children with ASD.

This study provides information about the experiences of mothers in at least four areas. First, the key area of investigation is specifically of **mothers** of children with ASD in Oman. Previous research has tended to focus on the experiences of "parents" and "professionals" see Chapter 2, section 2.6). Thus, the choice of mothers as participants in this study adds a voice for the research in Oman.

Second, this study explored the experiences of mothers in their choices and decisions about their children's educations. These choices and decisions included looking for services available for their children in their areas. I reported knowledge from the outcomes of mothers' experiences that provides an understanding of the influences that affect their choice, such as finance, child and family as well as their emotions. When Omani mothers choose a school/ centre to support their children's development, it is not an easy process, and there are obviously emotional and practical burdens on them seeking services, with limited support or information available from the community and family.

Third, another theoretical contribution relates to the concept of support. This study identified different types and levels of support that mothers experienced in their lives with their children with ASD, in particular, regarding decisions and choices for their education (see Chapter 6, section 6.5 and figure 6.2).

A fourth theoretical contribution concerns the positioning of knowledge is about mothers' diagnosis-seeking behaviour. Many mothers in my current study made frequent trips abroad to seek medical opinions about the possible treatments for their children with ASD. This seems to mean that mothers saw knowledge about ASD as being situated not in Oman, but in other countries. Different mothers mentioned that they had made trips to the UK, Thailand, India, UAE, Jordan and Egypt. The mothers travelled either because the country, such as UAE, was close to Oman, or because they believed that the professionals in those countries were more specialized in the subject of ASD. They also travelled for other reasons, such as to study abroad. The diagnosis-seeking behaviour has not been reported in previous research inside or outside Oman. This also to be driven from the mothers operate within a medical understanding for ASD.

7.3.2 Methodological contributions

One methodological contribution relates to the focus on mothers as participants, a group of people that had not been approached in Omani research in relation to their experiences about their lives with a child with ASD or their choices and decisions for their children’s education. Having mothers as participants in research in Oman is new, because most research in Oman investigated parents of children with ASD (see section 2. 6). Though choosing mothers as participants is not new in research in other countries, it was useful to focus on this group in Oman.

Another methodological contribution relates to the narrative methodological design as there has not been other narrative research in this area of ASD and mothers in Oman. Further, the use of different data collection methods, such as story narration and building-rapport days, shows creativity in designing research to advance a richer understanding of the investigated area. These methods were used in order to carry out in-depth qualitative investigations about mothers’ experiences and to explore their perceptions and feelings about their lives with children with ASD; the mothers were able to express themselves in the story narration and in the interviews. In addition, these methods are new in Oman. Moreover, the day has not been used in other research with mothers of children with ASD in others studies internationally.

This study also has a number of implications for educational policies and practices in the Omani context as the following section highlights.

7.4 Implications and recommendations for policy and practice

The study findings have implications for policy- and decision-makers, as well as professionals, organisations and Omani ministries, such as the Ministry of Education (MOE), the Ministry of Health (MOH) and the Ministry of Social Development (MOSD). There are also implications for the educational system and the community. The study noted that mothers, through their experiences and daily interaction with professionals, encountered a variety of organisations whose policies and practices affected their decisions. The study suggests a number of recommendations in this regard as illustrated in figure (7.1) and discussed in detail below.

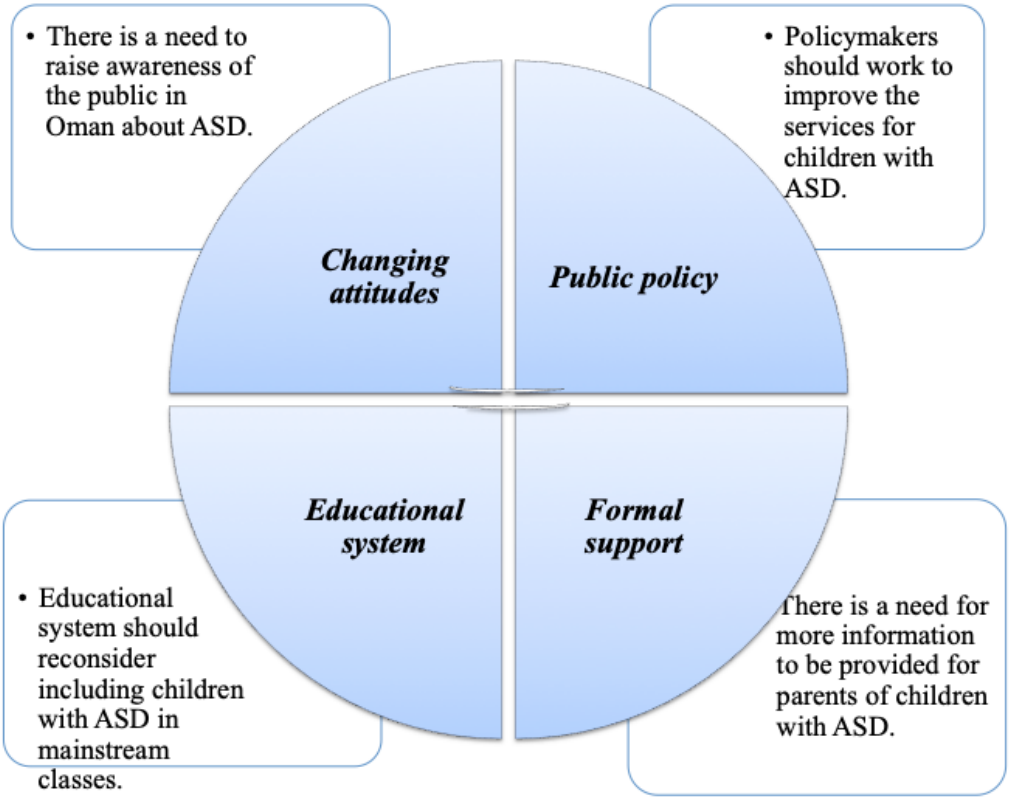


Figure 7.1: Study implications and recommendations for policy

Public policy

The current study has a number of implications and recommendations for policy in relation to public policy and services in education, health and social services for children with ASD and their families. One of the issues that it has identified is the limited services for children with ASD and their parents/mothers in Oman. So, according to mothers in the currents study, more services are needed for children with ASD. In order to improve the current situation, this study suggests that policy makers at the MOH need to examine the policy of diagnosing children with ASD, as facilities for the diagnosis of this condition are limited to only two hospitals in Oman. More diagnostic services could be considered in different areas. MOE in Oman assesses special classes for children with ASD, and MOSD assesses the availability of special centres. According to the current study most of the centres are located in the capital city, thus there is a need to establish more centres elsewhere.

Besides the quality of these services, such as that for diagnosis, that need to be revised by the three ministries (MOH, MOE, and MOSD), the competences of professionals in centres and special classes in mainstream schools need to be improved. This could happen through more collaboration between the three ministries to bridge any gap between the services available for those children and their families. For example, they could collaborate regarding the training for parents of children with ASD in order to decide their needs and could actively work in order to support those children and their families. In general, policy should enable the identification of the needs of children and their families, together with ways of meeting these needs in the aspects of education, services and support.

In all relevant contexts, the understanding and the expectations of education for children with ASD should be reviewed. The current meaning of ‘education’ is more related to developing academic education rather than developing children’s life skills. This study found that the meaning of education for children with ASD, according to their mothers, is to develop their life skills. The Ministry of Education started a pilot project in 2017 to include children with ASD who could be integrated into mainstream classes in mainstream schools (see Chapter 5, section 5.5.3), and this was mentioned by some mothers in this study. As reported by some mothers, this project, however, was stopped for financial reasons. It seemed to be promising for some mothers because children, no matter what level of ASD, were included in public mainstream schools, which had a positive effect on some mothers’ feelings. This project could be reconsidered and restarted if the reason for stopping it was related to budget issues rather than its practicality.

There also seems to be a necessity for new legislation to incorporate the voices of parents of children with ASD, so that their views are clearly stated and highly valued in the decisions relating to their children’s placement, their future and the development of services for children with disabilities in general. For example, when thinking of new projects, there should be collaboration between the parents of children with ASD and policy makers in order to plan, apply and evaluate new projects or programmes related to them. The parents of children with ASD should be included in the discussion of the issue related to children with ASD.

Since the current research provided an idea of the support needed for families for children with ASD, there could be a recommendation for the policy makers in Oman to think about what formal support these children with ASD and their families need. The knowledge about family support could be distributed among practitioners and professionals who work with families of children with ASD so that they become more informed about those families' needs.

Formal support

Formal support was distinguished from informal support (see Chapter 6, section 6.5). Formal support is more related to institutions, organizations and the public, while informal support is more connected to immediate and extended family. A lack of satisfaction with the formal support they received was evident among the majority of the mothers in the current study. They highlighted the need for different types of support, including social, emotional and financial support. Many parents asked for formal support from professionals whenever they felt they needed it. One aspect of support is information - its availability and accessibility. In the current study, mothers noted a lack of information about ASD and the services available for children with ASD. Information regarding ASD, and the details of organisations and associations that are relevant to children with ASD could be stated clearly for parents. For example, there could be a pamphlet outlining websites and support that parents can access. The Ministry of Health, for example, could inform parents about their rights and the health services for children with ASD and their parents.

In addition, there is a need for other forms of support (such as social and physical support), particularly a need for extensive support in rural areas. One mother in a rural area reported that she suspected her child behaviours, so she immediately tried to contact the professionals to identify her child's 'condition', but she did not receive the support she needed through the formal organization, which led her to travel abroad.

Educational system

The current Omani educational system established the programme of including children with disabilities in special classes in mainstream schools in 2008 (MOE, 2018). This was in addition to the pilot project in 2017 that was piloted for one year and stopped because for financial reasons (see the section above about public policy). However, according to the findings of this study, this programme seems to be excluding children with ASD from being in mainstream schools. Therefore, there would seem to be a need to reconsider including this group of children in these special classes. In addition, it may be important to rethink the theory and practice around education and ASD in Oman, as it seems to be assumed that children with ASD are a group that cannot be included with other typically developing children. The current study reported that some children were able to develop their academic and social skills when they were included in these classes and the 'inclusive' atmosphere seemed to support some children with ASD.

Changing attitudes

From a social model perspective, this study seems to highlight the need to raise public awareness of ASD in Oman in order to change the current commonly 'negative' attitude towards children's behaviour in public places, as reported by mothers in this study. The need for medical model is important for providing the services that meet the needs of the children with ASD. However, it seems necessary to raise the awareness of some professionals in schools and centres so that they start to involve mothers and families in identifying the needs of the children with ASD. This is something that could happen through the provision of information about ASD to every citizen in Oman, as well as to mothers of children with ASD and their immediate and extended family members. I am aware that changing attitude is not at all straightforward, but workshops and seminars in public places, such as schools and hospitals, might help people understand ASD. The results of this study suggest that organisations, and society in general, should consider the experiences and the feelings of parents of children with ASD, and should, if possible, adopt a more inclusive approach in some public services and in practices relating to ASD.

7.5 The strengths and limitations of this study

This study involved myself as an insider researcher, which could be considered as both a strength and a limitation. Conducting research as an insider researcher who is herself the mother of a child with ASD, with some experiences in common with the participants and familiarity with the context, was both challenging and beneficial for me and has potential advantages and disadvantages. The advantage is the familiarity of the researcher for the topic, the setting, links between situations and events, but there is a risk of bias from the researcher and/or the participants. This insider/outsider position helped me to understand the meaning that mothers constructed in their stories, interviews in building-rapport days. In addition, mothers seemed more willing to express themselves to an insider than to an outsider; they might, for example, have felt connected to me as I have similar experiences to theirs.

A possible limitation of the study also relates to the researcher role, my being a novice researcher in the field of ASD. Although I am the mother of a child of ASD, I work in the field of teaching English to speakers of other languages and have had only a brief opportunity to engage with the field of ASD and education prior to my doctoral study. It is possible that if I had more time to be immersed in the field, and further communication with professionals in ASD, this would have helped me to understand more about ASD.

Possible limitations also relate to the choice and nature of participants. The study involved only mothers. The perspective of fathers of children of ASD, siblings and other family members may have added another aspect to the picture. I chose mothers because I am the mother of a child with ASD; I wanted to give a voice to mothers because they are the main carers of children with ASD in Oman and have not been heard in Oman.

A further possible limitation with regard to participants is that, although the mothers in this study were from different regions in the Sultanate of Oman, the majority of them were from urban areas such as Muscat, Sohar and Salalah. Being within urban areas may mean that the mothers are therefore closer to the few ASD services that are available in Oman (see chapter 5). It is possible that mothers living in more rural areas have even more access to services, such as schools that have staff with training in supporting the needs of children with ASD. Mothers who live in places where the services are limited may have a very different experience from that of the mothers who participated in this study.

Participants in this study were all mothers, which brings both strengths and limitations to the study. When all of the participants share common characteristics, it gives weight to the findings being representative of the group. However, this makes it less possible to assume that the findings can be generalized to other people who do not share these characteristics.

The findings revealed a theme about (dis)satisfaction with services, which was common in the interviews with many of the mothers. I did not ask them in the interviews to rate their satisfaction regarding the services they or their children received, but could have asked them to do so, or to elaborate more on their (dis)satisfaction.

It is possible to say that the methods and accompanying vivid, in-depth responses of mothers in this study give significant weight to the findings. Nevertheless, the small sample size of the study may be considered to be a limitation. The findings cannot be generalized to the entire population of Omani mothers of children with ASD. Generalization was not, however, my aim for this study. On the other hand, the small sample size could be a strength to the study to provide some indications about the broader context of Oman, which is a necessity in a small community such as Oman.

One limitation relates to the translation of the data. As mentioned in the methodology chapter, the majority of mothers used Arabic to write or record their stories in phase 1 and in the interviews in phase 2. There were 23 stories written or recorded by mothers in Arabic while two stories were originally written by mothers in English because it was their choice of language. It is possible that this culminated in a language barrier of sorts, which may have influenced the results. There were many potential differences in the meanings of some words, such as' specialists/ professional', 'inclusion' and the meaning of ASD itself. For example, there are two words that are used in Arabic for ASD. The word (Tayf tawahd) could mean mild ASD, and the word (tawahd) could mean severe.

7.6 Recommendations for further research

Despite the limitations of this study, this research makes a number of contributions to the understanding of the experiences of mothers raising a child diagnosed with ASD. This section provides some ideas for future research based on the findings, and study recommendations for policy and practice.

The research explores the experiences of mothers raising children with ASD and, whilst this has been the main subject of research in various regions of the globe, to my knowledge no study exists that describes the experiences of mothers living in Oman. This study provides a glimpse into how some members of this culture may experience raising a child with ASD. As expressed in section (7.4) above, it is hoped that once this research is shared with those in the country, it may serve to better inform the need for services and supports for mothers and families raising a child diagnosed with ASD living in Oman. Further, it is hoped that this research may encourage other professionals in Oman to continue to explore the experiences of families of children diagnosed with ASD in order to better understand how to approach service delivery.

Fathers of disabled children have a vital contribution to make and have been neglected in this study. One of the suggestions for future research is to explore the experiences, perceptions and feelings of fathers living with children with ASD in Oman. The results of such a study could then be compared with those found in the current study, to see if fathers face challenges similar to or different from those of the mothers in this study.

The impact of ASD among family members, such as siblings, or other family members such as grandparents or aunts and uncles, is important as well, and was mentioned by some mothers in this study. Further studies might be able to derive additional insights into family systems and to explore family members' roles in the support of mothers. It would be particularly interesting to see if they have shared perceptions and feelings about their lives with children with ASD.

My sample focused on mothers of a school age child with ASD. I gathered some other information, such as the age of the child, the level of ASD (as described by the mother) and socioeconomic level (see Appendix 11), but I did not use these variables as criteria to determine my sample. However, marital status was not included in the demographic data, although the findings show that it seemed to have some relationship with the support mothers received and also seemed to have some influence on their choices and decisions. Further research is needed to explore this, using purposive sampling with specific criteria related to marital status.

The 'level' of ASDs might affect the decisions and choices that mothers have to make in order to choose the educational placement for them. The results of the current study showed that there was some impact. For example mothers who described their children as they had severe condition of ASD, did not want them to go to a mainstream school; however, it would be interesting to study the impact of the severity of ASD on mothers' lives, choices and decisions.

While this study explored the experiences of mothers, it did not examine or try to explain why such experiences took place or why there may be differences between participants. It would be interesting for further studies to investigate conditions that contribute to the experiences that may be found in the past, present and future of the lives of mothers with children with ASD.

It would also be valuable research to investigate the significance of children's age in mothers' or parents' decisions and choices for their children with ASD. Thus, the aim of research could explore whether parents make different decisions at different stages or ages, or whether these decisions are influenced differently.

Generalisation was not the aim of this study, as mentioned earlier, therefore there is a need for larger scale research to provide more results that could be generalised for the population of mothers of children with ASD in Oman.

This study contributes to understanding around support for mothers of children with ASD in Oman and recommends the establishment of formal support services there. It would be interesting for further research to be conducted which explores the effectiveness of support for parents’ wellbeing.

The findings in this study suggest that many mothers had hopes for the future of their children with ASD, which for some included their child talking, being independent or getting a job. Conducting a longitudinal study with these mothers, or a similar sample, would be interesting in order to study their lives over time and identify whether there are any changes in their hopes

This study has theoretical contribution in the area of mother experiences since it explored the reaction of mothers of children with ASD and investigated the process they seek in order to find a diagnosis for their children’s behaviour. The benefit of this knowledge is for professionals in Oman to consider when they plan services for parents of children with ASD.

This study also explored several unique experiences of mothers, including their experience from conception to first noticing developmental delays, as well as the help-seeking behaviours that followed the development of these concerns. Further research in this area may help professionals to better understand the kinds of behaviours that stand out most to parents when watching their child grow, and also the kinds of feelings and experiences they initially have that set the process of evaluation and diagnosis in motion. Additionally, this study was among the first to ask mothers to not only describe their vision of the future for their children, but also to ask them what advice they would give to another mother whose child had just received a diagnosis. Further research in this area would help us better understand the priorities parents have for their children’s development, which is essential for planning ‘treatment’. It would also be useful to know what kind of information or words of comfort the participants would feel was important for mothers of newly diagnosed children to hear; this could then perhaps better inform professionals’ practice when delivering the diagnosis. Such research provides knowledge for scholars and researchers who are interested in the area of mothers' experiences.

In addition, public hospitals should be equipped with more doctors and health professionals to speed up the diagnosis process in order to prevent parents from seeking private help or travelling abroad to seek diagnosis, which is very costly. For example, there is a need to adopt a social model approach to ASD research rather than a medical model. The start to this process could be done through contacting the research group in Oman, and exploring and funding more research with qualitative methods, exploring the experiences of all stakeholders working in the field of ASD. The research could develop and then evaluate some training for parents, the experts in their child's care, and also for practitioners working with children with ASD.

7.7 Personal reflection

The process of carrying out this project has been a great learning opportunity that has influenced me as a researcher and as the mother of a child with ASD. Regardless of my experiences as the mother of such a child, who was 12 to 17 years old over the period of the research, the past five years of my life have been a time of continuous reading, thinking and reflecting on ASD. I faced many challenges while conducting this research, but it has developed my understanding as a researcher, as the mother of a child with ASD, and maybe also as an educator.

First, at the research level, the completion of this study has led to a great shift in the assumptions I used to have about the meaning of ASD, the level and types of support and the meaning of education for a child with ASD. I have been challenged and confronted by what I know and what I thought I knew and to go beyond it. This encouraged me to continuously think about what I was before my PhD and what I have tried hard to become while conducting this study, and maybe what should I do in the future. My current work is not relevant to this study, so at the beginning there were some contradictions with regard to the issues that I encountered when comparing my background as a trainer in Teaching English to Speakers of Other Languages (TESOL) to what I was planning to study. My bachelor's and master's degrees and my job were related to teaching and training TESOL. I was not confident in the field of ASD, regardless of my personal experience. I started to realize that the more I read and engaged in my project, the more I felt confident and secure in researching this area. I started to realize that it is important for a person to be skeptical about what is going around them, to look for meanings and to think from different angles. This helped me to always seek knowledge, evaluate various perspectives and to think critically about events around me and to always challenge my assumptions.

Most significantly, with the continuous support from my supervisors, experienced friends and continuous discussion with colleagues, I have developed many research skills in order to learn how to present my work in a better way. Thus, I have had the opportunity to present my work at conferences in Oman and in the UK. I am also hoping to publish some of this thesis. Sharing my work with a wider audience was invaluable for me to develop my work and to develop my presentation skills.

Second, exploring mothers' experiences did not only encourage me to finish my research for the sake of my PhD, it became a part of me as a mother and an educator. I started to think about starting a voluntary support group to contact mothers of children with ASD and maybe different disabilities, to be beside them and to support them, and maybe one day I will be able to establish the first formal support in Oman funded by the government. I started to think about how the parents of children with different disabilities need to see that, regardless of the challenges that we have with our children, we can be productive. I started to think about myself being an empowered person in Omani society. Making Omani society better became a frequent topic with my family and my colleagues. Many of them interacted energetically in the discussion and said that there is a serious need for these ideas in our society. Such comments have always encouraged me to keep going and to be enthusiastic and optimistic, and one day I will do something for these mothers in Oman. Being aware of the issues is the first step towards development, and this encourages me to build an awareness about the issue of ASD in Oman with my children, family, colleagues and, hopefully, one day with policy-makers in order to make a difference. I feel that ASD needs the opportunity for change, and I am now more determined to go back to my country and to continue exploring relevant topics about ASD and to make recommendations to policy-makers.

My personal experience of having a child with ASD provided me with strength in this study as I have an inside perspective regarding ASD and its impact on mothers. I know from my personal experience that my life was definitely affected by my son, so I can relate to those mothers experiencing similar situations. ASD definitely changes the entire family dynamics. I always have to think about new plans for my son in particular and for my family, hoping that these plans will make our family life as ‘normal’ as possible.

I have found that this study has developed me personally and professionally. The mothers’ stories offered an opportunity to ask many questions, which challenged the Omani education system that I am a part of. I knew from the beginning that providing support to mothers and families with children with ASD is not an easy task. In the past, I assumed that mothers were not seeking education for their children with ASD. For this reason, many of children were kept at home. After conducting this study, I have gained considerable insights into how mothers are doing their best to help their children with ASD and, if they were at home, this was for many reasons.

7.8 Conclusion

Conducting research on mothers with children with ASD in Oman was the focus of the study. Being the mother of child with ASD, I wanted to explore mothers’ experiences, perceptions and feelings about their lives and educational decisions and choices. I wanted to hear mothers’ voices about the services available for their children with ASD. This study adds to the body of knowledge regarding the understanding of mothers’ feelings and experiences of raising a child with ASD, and their perceptions and feelings about the support that is available. In addition, it adds to the body of knowledge about ASD in Oman, where the amount of research is still limited.

The study aimed to add to the knowledge about mothers of children with ASD in Oman by exploring three major topics. First, the study explored the experiences and the feelings of mothers in Oman from the birth of their child to the awareness of their child's diagnosis. Second, it explored the support that mothers did, or did not receive whether formally or informally. Third, it looked at the mothers' perception and experiences regarding the decisions and choices they had to make for their children's education. Mothers' narratives and interviews, and the days I spent with them, were rich in providing information for analysis and discussion, and they allowed me to understand their lives and their educational decisions.

The use of thematic analysis provided a deep understanding of the lives of mothers of children with ASD, their feelings and experiences, the support they received (or not), and their lives in relation to the choices and decisions for their children's education. Through this study, a better understanding has been acquired of what it means to be the mother of a child with ASD in the context of Oman. This is a context with theory and practice that are still very challenging for mothers in terms of accessing services and gaining education for their children. By listening to families and mothers and meeting their needs, Oman may be able to positively change both the theory and practice around ASD there. Each mother in the current study, with her experience, her perception and her feelings, has hopefully contributed to this change.

References

Al Bloushi, S. (2019). *The Experiences of Omani Mothers Caring for Children with Cerebral Palsy (CP): A Grounded Theory Study* (Doctoral dissertation, University of Manchester).

Al-Farsi, O. (2016). The Quality of life among Parents of Children with Autism Spectrum Disorder in Oman. Sultan Qaboos University. *Unpublished PhD* dissertation.

Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case–control study. *Neuropsychiatric disease and treatment*, *12*, 1943.

Al-Farsi, Y. M., Al Shafaee, M. A., Al-Lawati, K. S., Al-Sharbati, M. M., Al-Tamimi, M. F., Al-Farsi, O. A., & Al-Adawi, S. S. (2016). Awareness about autism among primary healthcare providers in Oman: A cross-sectional study. *Global Journal of Health Science*, *9*(6), 65-75.

Al-Farsi, Y. M., Al-Sharbati, M. M., Al-Farsi, O. A., Al-Shafaee, M. S., Brooks, D. R., & Waly, M. I. (2011). Brief report: Prevalence of autistic spectrum disorders in the Sultanate of Oman. *Journal of autism and developmental disorders*, *41*(6), 821-825.

Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al Shafaee, M. A., & Deth, R. C. (2011). Malnutrition among preschool-aged autistic children in Oman. *Research in Autism Spectrum Disorders*, *5*(4), 1549-1552.

Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al-Shafaee, M. A., Al-Khaduri, M. M., & Deth, R. C. (2012). Effect of suboptimal breast-feeding on occurrence of autism: A case–control study. *Nutrition*, *28*(7-8), e27-e32.

Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M. A., Al-Farsi, O. A., Al-Khaduri, M. M., & Deth, R. C. (2013). Levels of heavy metals and essential minerals in hair samples of children with autism in Oman: a case–control study. *Biological trace element research*, *151*(2), 181-186.

Al-Farsi, Y. M., Waly, M. I., Deth, R. C., Al-Sharbati, M. M., Al-Shafaee, M., Al-Farsi, O., & Al-Adawi, S. (2013). Low folate and vitamin B12 nourishment is common in Omani children with newly diagnosed autism. *Nutrition*, *29*(3), 537-541.

Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M., Al-Farsi, O., Al-Fahdi, S., & Al-Adawi, S. (2013). Variation in socio-economic burden for caring of children with autism spectrum disorder in Oman: caregiver perspectives. *Journal of autism and developmental disorders*, *43*(5), 1214-1221.

Al-Kindi, N. M., Al-Farsi, Y. M., Waly, M. I., Al-Shafaee, M. S., Bakheit, C. S., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Comparative assessment of eating behavior among children with autism to typically developing children in Oman. *Canadian Journal of Clinical Nutrition*, *4*, 51-64.

Al-Mamari, N. (2016). Prevalence of autism in Oman. *OMAN NEWSPAPER, February.*

Al Maskari, T. S. (2018). *A mixed methods study exploring the barriers and facilitators of screening for autism spectrum disorder in Oman.* PhD thesis.

Al-Riyami, A. (2013). Oman's Autistic Children dire in need. *Oman Observer*, January.

Al-Sharbati M., Al-Farsi YM., Al-Sharbati ZM., Ouhtit A., Waly MI., Al-Khaduri MM., et al (2012). Autistic Spectrum Disorder (ASD) Among Omani Children Below 6 Years: A five-year retrospective descriptive study.

Al-Sharbati, M. M., Al-Farsi, Y. M., Ouhtit, A., Waly, M. I., Al-Shafaee, M., Al-Farsi, O., & Al-Adawi, S. (2015). Awareness about autism among school teachers in Oman: A cross-sectional study. *Autism*, *19*(1), 6-13.

Alfawair, A., & Al Tobi, A. (2015). Special needs education in Sultanate of Oman: Past, present and future. *Scholars Journal of Arts, Humanities and Social Sciences*, *3*, 415-22.

Al Zidjaly, N. (2016). *Disability, discourse and technology:* Agency and inclusion in (Inter) action. Springer.

Association, American Psychiatric. (2013). *Diagnostic and statistical manual of mental disorders*. American Psychiatric Publishing.

Arellano, A., Denne, L. D., Hastings, R. P., & Hughes, J. C. (2019). Parenting sense of competence in mothers of children with autism: Associations with parental expectations and levels of family support needs. *Journal of Intellectual & Developmental Disability*, *44*(2), 212-218.

Atkinson, R., & Flint, J. (2001). Accessing hidden and hard-to-reach populations: Snowball research strategies. *Social research update*, *33*(1), 1-4.

Band, S., Lindsay, G., Law, J., Soloff, N., Peacey, N., Gascoigne, M., & Radford, J. (2002). Are health and education talking to each other? Perceptions of parents of children with speech and language needs. *European Journal of Special Needs Education*, *17*(3), 211-227.

Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological medicine*, *45*(3), 601.

Bazna, M. S., & Hatab, T. A. (2005). Disability in the Qur'an: The Islamic alternative to defining, viewing, and relating to disability. *Journal of Religion, Disability & Health*, *9*(1), 5-27.

Beckett, A. E., & Buckner, L. (2012). Promoting positive attitudes towards disabled people: definition of rationale and prospects for anti-disablist education. *British Journal of Sociology of Education*, *33*(6), 873-891.

Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of autism and developmental disorders*, *36*(5), 685-695.

Benson, P. R. (2018). The impact of child and family stressors on the self-rated health of mothers of children with autism spectrum disorder: Associations with depressed mood over a 12-year period. *Autism*, *22*(4), 489-501.

Benson, P., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism*, *12*(1), 47-63.

Bent, C. A., Barbaro, J., & Dissanayake, C. (2017). Change in autism diagnoses prior to and following the introduction of DSM-5. *Journal of Autism and Developmental Disorders*, *47*(1), 163-171.

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, *50*(3), 184-198.

Blane, K. K., & Borden, M. C. (2008). The importance of early intervention for autism. *Brown University Child and Adolescent Behavior Letter*, *24*(6).

Bolourian, Y., Stavropoulos, K. K., & Blacher, J. (2019). Autism in the classroom: Educational issues across the lifespan. In *Autism Spectrum Disorders-Advances at the End of the Second Decade of the 21st Century*. IntechOpen.

Bosetti, L. (2004). Determinants of school choice: Understanding how parents choose elementary schools in Alberta. *Journal of Education Policy*, *19*(4), 387-405.

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices:'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: care, health and development*, *42*(6), 784-797.

Bradshaw, J., Bearss, K., McCracken, C., Smith, T., Johnson, C., Lecavalier, L., & Scahill, L. (2018). Parent education for young children with autism and disruptive behavior: Response to active control treatment. *Journal of Clinical Child & Adolescent Psychology*, *47*(sup1), S445-S455.

Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: is it time for an alternative model of disability? *Disability & Society*, *17*(7), 825-843.

Brewin, B. J., Renwick, R., & Fudge Schormans, A. (2008). Parental perspectives of the quality of life in school environments for children with Asperger syndrome. *Focus on Autism and other developmental disabilities*, *23*(4), 242-252.

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, *24*(1), 38-49.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, *8*(4), 409-423.

Bruner, J. (2004). Life as narrative. *Social research: An international quarterly*, *71*(3), 691-710.

Bryman, A. (2012). *Social research methods*, 4th Edition. New York: Oxford University Press Inc.

Cairney, T. H. (2000). Beyond the classroom walls: The rediscovery of the family and community as partners in education. *Educational review*, *52*(2), 163-174.

Campisi, L., Imran, N., Nazeer, A., Skokauskas, N., & Azeem, M. W. (2018). Autism spectrum disorder. *British medical bulletin*, *127*(1).

Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: Parents’ experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language & Communication Disorders*, *51*(3), 328-338.

Carpenter, L. A., Boan, A. D., Wahlquist, A. E., Cohen, A., Charles, J., Jenner, W., & Bradley, C. C. (2016). Screening and direct assessment methodology to determine the prevalence of autism spectrum disorders. *Annals of epidemiology*, *26*(6), 395-400.

Cianfaglione, R., Hastings, R. P., Felce, D., Clarke, A., & Kerr, M. P. (2015). Psychological well-being of mothers and siblings in families of girls and women with Rett syndrome. *Journal of autism and developmental disorders*, *45*(9), 2939-2946.

Clough, P., & Nutbrown, C. (2002). The index for inclusion: Personal perspectives from early years educators. *Early Education*, *36*(Spring), 1-4.

Cohen, L., Manion, L.& Morrison, K. (2018). *Research methods in Education* (7th ed). New York: Taylor & Francis.

Coleman, J. S., & Jones, C. G. (1988). Plant stress and insect performance: cottonwood, ozone and a leaf beetle. *Oecologia*, *76*(1), 57-61.

Connecticut State Department of Education, (2005). Guidelines for Identification and Education of Children and Youth with Autism, July. Revised, 2011.

Connolly, M., & Gersch, I. (2016). Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. *Educational Psychology in Practice*, *32*(3), 245-261.

Connolly, T., & Zeelenberg, M. (2002). Regret in decision making. *Current directions in psychological science*, *11*(6), 212-216.
Cook, K. A., & Willmerdinger, A. N. (2015). The history of Autism. Narrative Documents. Book 1. http://scholarexchange.furman.edu/schopler-about/1

Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative inquiry*, *9*(3), 335-354.

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: a systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, *19*(4), 356-366.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into practice*, *39*(3), 124-130.

Creswell, J. W. (2006). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches (2nd ed.).* London: Sage.

Creswell, J. (2013). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches* (3rd Ed.). London: Sage Publications.

Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

Crossley, M. L. (2010). *Introducing narrative psychology: Self, trauma and the construction of meaning. (2nd ed.)***.** Buckingham: Open University Press.

Dauber, S. L., & Epstein, J. L. (1993). Parents' attitudes and practices of involvement in inner-city elementary and middle schools. *Families and schools in a pluralistic society*, 53-71.

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of autism and developmental disorders*, *38*(7), 1278.

Davis, L. J. (2013). The End of Identity Politics: On Disability as an Unstable Category. *The disability studies reader*, 263.

Delmolino, L., & Harris, S. L. (2012). Matching children on the autism spectrum to classrooms: A guide for parents and professionals. *Journal of Autism and Developmental Disorders*, *42*(6), 1197-1204.

DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative health research*, *25*(4), 569-583.

Dieleman, L. M., Soenens, B., Vansteenkiste, M., Prinzie, P., Laporte, N., & De Pauw, S. S. (2019). Daily sources of autonomy-supportive and controlling parenting in mothers of children with ASD: The role of child behavior and mothers' psychological needs. *Journal of autism and developmental disorders*, *49*(2), 509-526.

Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Focus on practice: Living with children diagnosed with autistic spectrum disorder: parental and professional views. *British Journal of Special Education*, *37*(1), 13-23.

Dobbins, M., & Abbott, L. (2010). Developing partnership with parents in special schools: parental perspectives from Northern Ireland. *Journal of Research in Special Educational Needs*, *10*(1), 23-30.

Dowling, M., & Dolan, L. (2001). Families with children with disabilities-inequalities and the social model. *Disability & Society*, *16*(1), 21-35.

Drake, R. (1999) *Understanding Disability Policies*. London: MacMillan.

Duncan, N. (2003). Awkward customers? Parents and provision for special educational needs. *Disability & Society*, *18*(3), 341-356.

Dunst, C. J., Trivette, C. M., & Masiello, T. (2011). Exploratory investigation of the effects of interest-based learning on the development of young children with autism. *Autism*, *15*(3), 295-305.

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of intellectual disability research*, *49*(9), 657-671.

Easter Seals. (2009). Research examines autism-associated concern: Easter Seals study quantifies anecdotal evidence. *ASHA Leader, 14(2),* 22.

Ekas, N. V., Ghilain, C., Pruitt, M., Celimli, S., Gutierrez, A., & Alessandri, M. (2016). The role of family cohesion in the psychological adjustment of non-Hispanic White and Hispanic mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *21*, 10-24.

Ekas, N. V., Timmons, L., Pruitt, M., Ghilain, C., & Alessandri, M. (2015). The power of positivity: Predictors of relationship satisfaction for parents of children with autism spectrum disorder. *Journal of autism and developmental disorders*, *45*(7), 1997-2007.

Faras, H., Al Ateeqi, N., & Tidmarsh, L. (2010). Autism spectrum disorders. *Annals of Saudi medicine*, *30*(4), 295-300.

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, *31*(7), 1011-1027.

Fernańdez-Alcántara, M., García-Caro, M. P., Pérez-Marfil, M. N., Hueso-Montoro, C., Laynez-Rubio, C., & Cruz-Quintana, F. (2016). Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD). *Research in developmental disabilities*, *55*, 312-321.

Findler, L., Jacoby, A. K., & Gabis, L. (2016). Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Research in developmental disabilities*, *55*, 44-54.

Finke, E. H., Kremkow, J. M., Drager, K. D., Murillo, A., Richardson, L., & Serpentine, E. C. (2019). "I Would Like for My Child to be Happy with His Life": Parental Hopes for Their Children with ASD Across the Lifespan. *Journal of autism and developmental disorders*, *49*(5), 2049-2068.

Fisher, P., & Goodley, D. (2007). The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of health & illness*, *29*(1), 66-81.

Flewitt, R., & Nind, M. (2007). Parents choosing to combine special and inclusive early years settings: the best of both worlds? *European Journal of Special Needs Education*, *22*(4), 425-441.

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of autism and developmental disorders*, *33*(4), 365-382.

Fong, L., Wilgosh, L., & Sobsey, D. (1993). The experience of parenting an adolescent with autism. *International Journal of Disability, Development and Education*, *40*(2), 105-113.

Foot, H., Howe, C., Cheyne, B., Terras, M., & Rattray, C. (2000). Pre-school Education: Parents' preferences, knowledge and expectations Enseignement Prescolaire: Preferences, connaissances et attentes des parent Educacio´ n Preescolar: Preferencias, conocimiento y expectativas de los padres. *International Journal of Early Years Education*, *8*(3), 189-204.

Freedman, R. I., Litchfield, L. C., & Warfield, M. E. (1995). Balancing work and family: Perspectives of parents of children with developmental disabilities. *Families in Society*, *76*(8), 507-514.

Gabel, S.L. (2018), Shatter Not the Branches of the Tree of Anger: Mothering, Affect, and Disability. *Hypatia*, 33, pp.553-568. doi:10.1111/hypa.12410

Garfinkle, A. N., & Schwartz, I. S. (2002). Peer imitation: Increasing social interactions in children with autism and other developmental disabilities in inclusive preschool classrooms. *Topics in Early Childhood Special Education*, *22*(1), 26-38.

Godina, L. (2012). Religion and parenting: Ignored relationship? Child and Family Social Work Gottlieb, R. S. (2002). The tasks of embodied love: moral problems in caring for children with disabilities. *Hypatia*, 17(3), pp.225-236.

Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social sciences*, *7*(8), 133.

Goin-Kochel, R. P., Myers, B. J., Hendricks, D. R., Carr, S. E., & Wiley, S. B. (2007). Early responsiveness to intensive behavioural intervention predicts outcomes among preschool children with autism. *International Journal of Disability, Development and Education*, *54*(2), 151-175.

Gomes, P. T., Lima, L. H., Bueno, M. K., Araújo, L. A., & Souza, N. M. (2015). Autism in Brazil: a systematic review of family challenges and coping strategies. *Journal de Pediatria (Versão em Português)*, *91*(2), 111-121.

Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction*. London: Sage.

Goodley, D. (2014). *Dis/ability Studies: Theorising Disablism and Ableism.* London: Routledge.

Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: studies in the Cultural Politics of Education*, *37*(1), 1-15.

Goodson, I. F., & Sikes, P. J. (2001). *Life history research in educational settings: Learning from lives*. Open University Press.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*, *24*(2), 105-112.

Greenspan, S. I., & Wieder, S. (2006). *Engaging autism: Helping children relate, communicate and think with the DIR floortime approach.* Cambridge, MA: Da Capo Lifelong Books.

Ha, S., Sohn, I. J., Kim, N., Sim, H. J., & Cheon, K. A. (2015). Characteristics of brains in autism spectrum disorder: structure, function and connectivity across the lifespan. *Experimental neurobiology*, *24*(4), 273-284.

Hadidi, M. S., & Al Khateeb, J. M. (2015). Special education in Arab countries: Current challenges. *International Journal of Disability, Development and Education*, *62*(5), 518-530.

Hadadian, A. (1994). Stress and social support in fathers and mothers of young children with and without disabilities. *Early education and development*, *5*(3), 226-235.

Halstead, E. J., Griffith, G. M., & Hastings, R. P. (2018). Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, *64*(4-5), 288-296.

Harrison, A. J., Long, K. A., Manji, K. P., & Blane, K. K. (2016). Development of a brief intervention to improve knowledge of autism and behavioral strategies among parents in Tanzania. *Intellectual and developmental disabilities*, *54*(3), 187-201.

Hartley, S. L., DaWalt, L. S., & Schultz, H. M. (2017). Daily couple experiences and parent affect in families of children with versus without autism. *Journal of autism and developmental disorders*, *47*(6), 1645-1658.

Hasnain, R., Shaikh, L. C., & Shanawani, H. (2008). Disability and the Muslim perspective: *An introduction for rehabilitation and health care providers*.

Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of autism and developmental disorders*, *35*(5), 635.

Hatcher, R. (1998). Class differentiation in education: rational choices?. *British journal of sociology of education*, *19*(1), 5-24.

Hays, S. (1998). *The cultural contradictions of motherhood*. Yale University Press.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*, *43*(3), 629-642.

Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. SAGE Publications Limited.

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Brief report: What happens when I can no longer support my autistic relative? Worries about the future for family members of autistic adults. *Journal of Autism and Developmental Disorders*, *47*(11), 3659-3668.

Hodgetts, S., McConnell, D., Zwaigenbaum, L., & Nicholas, D. (2017). The impact of autism services on mothers' psychological wellbeing. *Child: care, health and development*, *43*(1), 18-30.

Hoogsteen, L. (2010). The lived experience of parenting a child with autism in a rural area: making the invisible, visible.

Hoover-Dempsey, K. V., & Sandler, H. M. (1997). Why do parents become involved in their children's education? *Review of educational research*, *67*(1), 3-42.

Hoover-Dempsey, K.V., Whitaker, M.C., & Ice, C.L., (2010). Motivation and commitment to family–school partnerships. In S.L. Christenson & A.L. Reschly (Eds.). *Handbook of school–family partnerships*. New York: Routledge. pp. 30–60.

Horne, J., Corr, S., & Earle, S. (2005). Becoming a mother: Occupational change in first time motherhood. *Journal of Occupational Science*, *12*(3), 176-183.

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of child psychology and psychiatry*, *45*(2), 212-229.

Huang, C. Y., Yen, H. C., Tseng, M. H., Tung, L. C., Chen, Y. D., & Chen, K. L. (2014). Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders*, *44*(6), 1383-1390.

Hurlbutt, K. S. (2011). Experiences of parents who homeschool their children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *26*(4), 239-249.

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S. A., & Golden, K. J. (2018). Parenting stress and resilience in parents of children with Autism Spectrum Disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in psychology*, *9*, 280.

Jenkinson, J. C. (1998). Parent choice in the education of students with disabilities. *International Journal of Disability, Development and Education*, *45*(2), 189-202.

Johnston, D. D., & Swanson, D. H. (2003). Invisible mothers: A content analysis of motherhood ideologies and myths in magazines. *Sex roles*, *49*(1), 21-33.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of autism and developmental disorders*, *27*(1), 39-57.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of advanced nursing*, *34*(5), 582-592.

Kelly, M. P., Alireza, I., Busch, H. E., Northrop, S., Al-Attrash, M., Ainsleigh, S., & Bhuptani, N. (2016). An overview of autism and applied behavior analysis in the Gulf Cooperation Council in the Middle East. *Review Journal of Autism and Developmental Disorders*, *3*(2), 154-164.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, *13*(3), 317-336.

Knight, K. (2013). The changing face of the ‘good mother’: trends in research into families with a child with intellectual disability, and some concerns. Disability & Society, 28(5), pp.660-673.

Kidd, T., & Kaczmarek, E. (2010). The experiences of mothers’ home educating their children with autism spectrum disorder. *Issues in Educational Research*, *20*(3), 257-275.

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, *46*(3), 942-953.

Kivirauma, J., & Ruoho, K. (2007). Excellence through special education? Lessons from the Finnish school reform. *International review of education*, *53*(3), 283-302.

Klein, T. J., Al-Ghasani, T., Al-Ghasani, M., Akbar, A., Tang, E. & Al-Farsi, Y. (2015). A mobile application to screen for autism in Arabic-speaking communities in Oman. *The Lancet Global Health,* 3**,** S15.

Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities*, *14*(3), 150-158.

Kroeger, J., & Lash, M. (2011). Asking, listening, and learning: Toward a more thorough method of inquiry in home–school relations. *Teaching and Teacher Education*, *27*(2), 268-277.

Kübler-Ross, E. (2009). *Death: The final stage*. Simon and Schuster.

Kumar, R. (2019). *Research methodology: A step-by-step guide for beginners*. Sage Publications Limited.

Kurth, J. A., Mastergeorge, A. M., & Paschall, K. (2016). Economic and demographic factors impacting placement of students with autism. *Education and Training in Autism and Developmental Disabilities*, *51*(1), 3-12.

Kvale, S., & Brinkmann, S. (2009). Learning the craft of qualitative research interviewing. *Thousands Oaks: Sage Publications*.

Landsman, G.H. (1998). Reconstructing motherhood in the age of" perfect" babies: Mothers of infants and toddlers with disabilities. *Signs: Journal of Women in Culture and Society*, 24(1), pp.69-99.

Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities*, 26(2), 121-139.

Lareau, A., & Horvat, E. M. (1999). Moments of social inclusion and exclusion race, class, and cultural capital in family-school relationships. *Sociology of education*, 37-53.

Lee, J., Chang, S. H., & Haegele, J. A. (2016). Satisfaction of Parents of Children With Autism Toward Physical Education. *Research Quarterly for Exercise and Sport*, *87*(S2), A14.

Levin, A., & Scher, A. (2016). Sleep problems in young children with autism spectrum disorders: A study of parenting stress, mothers' sleep-related cognitions, and bedtime behaviors. *CNS neuroscience & therapeutics*, *22*(11), 921-927.

Li, A., Shaffer, J., & Bagger, J. (2015). The psychological well-being of disability caregivers: Examining the roles of family strain, family-to-work conflict, and perceived supervisor support. *Journal of occupational health psychology*, *20*(1), 40.

Lindsay, G. (2003). Inclusive education: A critical perspective. *British journal of special education*, *30*(1), 3-12.

Lilley, R. (2015). Trading places: Autism inclusion disorder and school change. *International Journal of Inclusive Education*, *19*(4), 379-396.

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development,* *24*(2), 1–21.

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The Lancet*, *392*(10146), 508-520.

Lu, M. H., Wang, G. H., Lei, H., Shi, M. L., Zhu, R., & Jiang, F. (2018). Social support as mediator and moderator of the relationship between parenting stress and life satisfaction among the Chinese parents of children with ASD. *Journal of autism and developmental disorders*, *48*(4), 1181-1188.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of health psychology*, *17*(5), 702-711.

Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of pediatric nursing*, *27*(3), 206-213.

Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, *12*(1), 41-51.

Machalicek, W., O'Reilly, M. F., Beretvas, N., Sigafoos, J., & Lancioni, G. E. (2007). A review of interventions to reduce challenging behavior in school settings for students with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *1*(3), 229-246.

Macy, M. W. (2006). Rational choice. *Contemporary social psychological theories*, 70-87.

Mandy, W., Charman, T., Puura, K., & Skuse, D. (2013). Investigating the cross-cultural validity of DSM-5 autism spectrum disorder: Evidence from Finnish and UK samples. *Autism*, *18*(1), 45-54.

Mantzoukas, S. (2008). Facilitating research students in formulating qualitative research questions. *Nurse Education Today*, *28*(3), 371-377.

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience bulletin*, *33*(2), 183-193.

Matson, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 418-425.

Matson, J. L., & Smith, K. R. (2008). Current status of intensive behavioral interventions for young children with autism and PDD-NOS. *Research in Autism Spectrum Disorders*, *2*(1), 60-74.

McDonald, C. A., Donnelly, J. P., Feldman-Alguire, A. L., Rodgers, J. D., Lopata, C., & Thomeer, M. L. (2019). Special education service use by children with autism spectrum disorder. *Journal of autism and developmental disorders*, *49*(6), 2437-2446.

McDonald, J. (2010). *Seeking progressive fit: a constructivist grounded theory and autoethnographic study investigating how parents deal with the education of their child with an Autism Spectrum Disorder (ASD) over time*. Perth: University of Western Australia.

McDonald, J. (2014). *How Parents Deal with the Education of Their Child on the Autism Spectrum*. Netherlands: Sense Publishers.

Mcleod, J. (2011). *Qualitative research in counseling and psychotherapy*. Sage.

Mercer, J. (2007). The challenges of insider research in educational institutions: Wielding a double-edged sword and resolving delicate dilemmas. *Oxford review of education*, *33*(1), 1-17.

Merriam, S. B., Johnson-Bailey, J., Lee, M. Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, *20*(5), 405-416.

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.

Midence, K., & O'neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, *3*(3), 273-285.

Ministry of Education. (2008). *Inclusive education in the Sultanate of Oman: national report.* Oman: Author.

Ministry of Education. (2015). *The annual educational statistics Book, 45ed*. Oman: Author.

Ministry of Education. (2019). *The annual educational statistics Book, 49ed*. Oman: Author.

Ministry of Information, (1991). *The Speeches of H.M. Sultan Qaboos bin said 1970-2020*

Ministry of Social development (2018). *The annual statistics Book*. Oman: Author.

Minnes, P., Perry, A., & Weiss, J. A. (2015). Predictors of distress and well-being in parents of young children with developmental delays and disabilities: the importance of parent perceptions. *Journal of Intellectual Disability Research*, *59*(6), 551-560.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(1), 293-303.

Myles, BS., Swanson, TC., Holvers, J., & Duncan, M. (2007). *Autism spectrum disorders: A handbook for parents and professionals*. Westport, CT: Praeger Publishers.

NAfW, (2002). *The National Basic Skills Strategy for Wales*. Cardiff. NAfW.

National research Council. (2001). *Educating children with autism. Committee on educational interventions for children with autism. Division of behavioral and social sciences and education.*

Nahal, M. S. H., Wigert, H., Imam, A., & Axelsson, Å. B. (2017). From feeling broken to looking beyond broken: Palestinian mothers' experiences of having a child with Spina Bifida. *Journal of Family Nursing*, *23*(2), 226-251.

Nahmias, A. S., & Mandell, D. S. (2014). A meta-analysis comparing parent- and clinician-implemented early interventions for children with autism spectrum disorders. *In International Meeting for Autism Research*.

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... & Reynolds, A. M. (2007). The epidemiology of autism spectrum disorders. *Annu. Rev. Public Health*, *28*, 235-258.

Norwich, B. (2002). Education, inclusion and individual differences: Recognising and resolving dilemmas. *British Journal of Educational Studies*, 50(4), 482-502.

Oliver, M. (2004). If I had a hammer: The social model in action. *Disabling barriers–Enabling environments*, *2*, 7-12.

Ouhtit, A., Al-Farsi, Y., Al-Sharbati, M., Waly, M., Gupta, I., Al-Farsi, O., ... & Al-Adawi, S. (2015). Underlying factors behind the low prevalence of autism spectrum disorders in Oman: Sociocultural perspective. *Sultan Qaboos University Medical Journal*, *15*(2), e213.

Parsons, S., & Lewis, A. (2010). The home-education of children with special needs or disabilities in the UK: views of parents from an online survey. *International Journal of Inclusive Education*, *14*(1), 67-86.

Parsons, S., Lewis, A., & Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey. *European Journal of Special Needs Education*, *24*(1), 37-58.

Pearson, J. N., & Meadan, H. (2018). African American Parents' Perceptions of Diagnosis and Services for Children with Autism. *Education and Training in Autism and Developmental Disabilities*, *53*(1), 17-32.

Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2016). Perceived friendship quality of children with autism spectrum disorder as compared to their peers in mixed and non-mixed dyads. *Journal of autism and developmental disorders*, *46*(4), 1334-1343.

Plummer, K. (2001). *Documents of life 2: An invitation to a critical humanism* (Vol. 2). Sage.

Poslawsky, I. E., Naber, F. B., Van Daalen, E., & Van Engeland, H. (2014). Parental reaction to early diagnosis of their children’s autism spectrum disorder: an exploratory study. *Child Psychiatry & Human Development*, *45*(3), 294-305.

Profanter, A. (2009). Facing the challenges of children and youth with special abilities and needs on the fringes of Omani society. *Children and Youth Services Review*, *31*(1), 8-15.

Pruitt, M. M., Willis, K., Timmons, L., & Ekas, N. V. (2016). The impact of maternal, child, and family characteristics on the daily well-being and parenting experiences of mothers of children with autism spectrum disorder. *Autism*, *20*(8), 973-985.

Punch, K. F. (2013). *Introduction to social research: Quantitative and qualitative approaches*. sage.

Quintero, N., & McIntyre, L. L. (2011). Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities. *Early Childhood Education Journal*, *38*(6), 411-420.

Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents’ experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, *66*, 101415.

Rajendran, G., & Mitchell, P. (2007). Cognitive theories of autism. *Developmental review*, *27*(2), 224-260.

Randall, M., Sciberras, E., Brignell, A., Ihsen, E., Efron, D., Dissanayake, C., & Williams, K. (2016). Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample. *Australian & New Zealand Journal of Psychiatry*, *50*(3), 243-253.

Reed, P., Osborne, L. A., & Corness, M. (2007). Brief report: Relative effectiveness of different home-based behavioral approaches to early teaching intervention. *Journal of autism and developmental disorders*, *37*(9), 1815-1821.

Reed, P., Picton, L., Grainger, N., & Osborne, L. A. (2016). Impact of diagnostic practices on the self-reported health of mothers of recently diagnosed children with ASD. *International journal of environmental research and public health*, *13*(9), 888.

Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health and Development*, *32*(3), 371-385.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.

Rieser, R. (2001). The struggle for inclusion: the growth of a movement. *Disability, politics and the struggle for change*, 132-148.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, *44*(7), 1609-1620.

Rizvi, S. (2017). Exploring British Pakistani mothers' perception of their child with disability: insights from a UK context. *Journal of Research in Special Educational Needs*, 17(2), pp.87-97.

Rizvi, S. (2018). There's never going to be a perfect school that ticks every box: minority perspectives of inclusion and placement preferences. *Journal of Research in Special Educational Needs*, 18, pp.59-69.

Robson, C. & McCartan, K. (2016). *Real world research*. 4th ed. United States: John Wiley & Sons.

Rogers, C. (2016) *Intellectual Disability and Being Human: a care ethics model*, London, Routledge

Rogers, C. (2011). Mothering and intellectual disability: partnership rhetoric?. *British Journal of Sociology of Education*, *32*(4), 563-581.

Rogers, C., (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education*, 34(3), pp.136-143.

Rogers, C. (2007). *Parenting and inclusive education: Discovering difference, experiencing difficulty*. Springer.

Rodger, S., Keen, D., Braithwaite, M., & Cook, S. (2008). Mothers' satisfaction with a home-based early intervention programme for children with ASD. *Journal of Applied Research in Intellectual Disabilities*, *21*(2), 174-182.

Roffeei, S. H. M., Abdullah, N., & Basar, S. K. R. (2015). Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *International journal of medical informatics*, *84*(5), 375-385.

Rozario, S. (2009). Allah is the scientist of the scientists: Modern medicine and religious healing among British Bangladeshis. *Culture and religion*, *10*(2), 177-199.

Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. S. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, *17*(2), 95-104.

Rutter, M. (2005a). A etiology of autism: findings and questions. *Journal of Intellectual Disability Research*, *49*(4), 231-238.

Rutter, M. (2005b). Incidence of autism spectrum disorders: changes over time and their meaning. *Acta paediatrica*, *94*(1), 2-15.

Ryan, S. (2005). ‘People don't do odd, do they?’ Mothers making sense of the reactions of others towards their learning disabled children in public places. *Children's Geographies*, *3*(3), 291-305.

Ryan, S. and Runswick-Cole, K., (2008). Repositioning mothers: Mothers, disabled children and disability studies. Disability & Society, 23(3), pp.199-210.

Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 43-53.

Samadi, S. A., & McConkey, R. (2018). Perspectives on Inclusive Education of Preschool Children with Autism Spectrum Disorders and Other Developmental Disabilities in Iran. *International journal of environmental research and public health*, *15*(10), 2307.

Salhia, H. O., Al-Nasser, L. A., Taher, L. S., Al-Khathaami, A. M., & El-Metwally, A. A. (2014). Systemic review of the epidemiology of autism in Arab Gulf countries. *Neurosciences*, *19*(4), 291.

Sandall, S., McLean, M. E., & Smith, B. J. (2000). *DEC recommended practices in early intervention/early childhood special education*. Sopris West, 4093 Specialty Pl., Longmont, CO 80504.

Sasson, N. J. (2006). The development of face processing in autism. *Journal of autism and developmental disorders*, *36*(3), 381-394.

Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. Teachers college press.

Shattuck, P. T., & Grosse, S. D. (2007). Issues related to the diagnosis and treatment of autism spectrum disorders. *Mental retardation and developmental disabilities research reviews*, *13*(2), 129-135.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: an outdated ideology?. In *Exploring theories and expanding methodologies: Where we are and where we need to go*. Emerald Group Publishing Limited.

Shirani, F., Henwood, K., & Coltart, C. (2012). Meeting the challenges of intensive parenting culture: Gender, risk management and the moral parent. *Sociology*, *46*(1), 25-40

Siebers, T. (2008). *Disability theory*. University of Michigan Press.

Silverman, D. (2013). *Doing qualitative research: A practical handbook*. SAGE Publications Limited.

Skidmore, D. (2004). *Inclusion: the dynamic of school development*. Maidenhead: Open University Press.

Slade, N., Eisenhower, A., Carter, A. S., & Blacher, J. (2018). Satisfaction with individualized education programs among parents of young children with ASD. *Exceptional Children*, *84*(3), 242-260.

Smallwood, M., Sareen, A., Baker, E., Hannusch, R., Kwessi, E., & Williams, T. (2016). Increased risk of autism development in children whose mothers experienced birth complications or received labor and delivery drugs. *ASN neuro*, *8*(4).

Smith, J., Cheater, F., & Bekker, H. (2015). Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations*, *18*(4), 452-474.

Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of autism and developmental disorders*, *38*(5), 876.

Sousa, A.C., (2011). From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interactio*n, 34(2), pp.220-243.

Stahmer, A. C. (2007). The basic structure of community early intervention programs for children with autism: Provider descriptions. *Journal of Autism and Developmental Disorders*, *37*(7), 1344-1354.

Starr, E. M., & Foy, J. B. (2012). In parents' voices: The education of children with autism spectrum disorders. *Remedial and Special Education*, *33*(4), 207-216.

Starr, E. M., Foy, J. B., Cramer, K. M., & Singh, H. (2006). How are schools doing? Parental perceptions of children with autism spectrum disorders, Down syndrome and learning disabilities: A comparative analysis. *Education and Training in Developmental Disabilities*, 315-332.

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, *20*(1), 39-51.

Strain, P. S. (2017). Four-year follow-up of children in the LEAP randomized trial: Some planned and accidental findings. *Topics in Early Childhood Special Education*, *37*(2), 121-126.

Sung, M., Ooi, Y. P., Law, G. C., Goh, T. J., Weng, S. J., & Sriram, B. (2013). Features of autism in a Singaporean child with Down syndrome.

Swick, K. J., & Hooks, L. (2005). Parental experiences and beliefs regarding inclusive placements of their special needs children. *Early Childhood Education Journal*, *32*(6), 397.

Tahmassian, K., Anari, M. A., & Fathabadi, M. (2011). The influencing factors of parenting stress in Iranian mothers. *European Psychiatry*, *26*(1), 19-24.

Tekinarslan, İ. Ç. (2018). Autism Spectrum Disorder: Experiences of Mothers before and after Their Children's Diagnosis and Implications for Early Special Education Services. *Journal of Education and Training Studies*, *6*(12), 68-81.

Tissot, C., & Evans, R. (2006). Securing provision for children with autistic spectrum disorders: The views of parents. *Perspectives in Education*, *24*(1), 73-86.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. McGraw-Hill Education (UK).

Thomas, C. (2002). *Disability theory: Key ideas*, issues and thinkers.

Thomas, G., (2009). *How to do Your Research Project*. London: Sage.

Tomeny, T. S., Baker, L. K., Barry, T. D., Eldred, S. W., & Rankin, J. A. (2016). Emotional and behavioral functioning of typically-developing sisters of children with autism spectrum disorder: The roles of ASD severity, parental stress, and marital status. *Research in Autism Spectrum Disorders*, *32*, 130-142.

Tomiyama, S., Kikuchi, M., Yoshimura, Y., Hasegawa, C., Ikeda, T., Saito, D. N., ... & Minabe, Y. (2018). Changes in maternal feelings for children with autism spectrum disorder after childbirth: The impact of knowledge about the disorder. *PloS one*, *13*(8), e0201862.

Traustadottir, R. (1991). Mothers Who Care: Gender, Disability, and Family Life. *Journal of Family Issues*, 12(2), pp.211-28.

Treloar, L. L. (2002). Disability, spiritual beliefs and the church: the experiences of adults with disabilities and family members. *Journal of Advanced Nursing*, 40(5), 594-603.

Turner, R. J., & Turner, J. B. (1999). Social integration and support. In *Handbook of the sociology of mental health* (pp. 301-319). Springer, Boston, MA.

Vanegas, S. B., & Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*, *19*(4), 286-327.

Van Herwegen, J., Ashworth, M., & Palikara, O. (2018). Parental views on special educational needs provision: cross-syndrome comparisons in Williams syndrome, Down syndrome, and autism spectrum disorders. *Research in developmental disabilities*, *80*, 102-111.

Vohs, K. D., Baumeister, R. F., Schmeichel, B. J., Twenge, J. M., Nelson, N. M., & Tice, D. M. (2014). Making choices impairs subsequent self-control: a limited-resource account of decision making, self-regulation, and active initiative.

Walker, J. M., Shenker, S. S., & Hoover-Dempsey, K. V. (2010). Why do parents become involved in their children's education? Implications for school counselors. *Professional School Counseling*, *14*(1), 2156759X1001400104.

Wall, K. (2010). *Autism and early years practice* London: SAGE Publications Ltd doi: 10.4135/9781446279557

Wang, T. H., Peng, Y. C., Chen, Y. L., Lu, T. W., Liao, H. F., Tang, P. F., & Shieh, J. Y. (2013). A home-based program using patterned sensory enhancement improves resistance exercise effects for children with cerebral palsy: a randomized controlled trial. *Neurorehabilitation and neural repair*, *27*(8), 684-694.

Wedell, K. (2008). Inclusion: Confusion about inclusion: patching up or system change?. *British Journal of Special Education*, *35*(3), 127-135.

Wengraf, T. (2006). *Qualitative Research Interviewing*, London: Sage.

White, M., White, M. K., Wijaya, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. WW Norton & Company.

Wilson, K. P., & Landa, R. J. (2019). Barriers to educator implementation of a classroom-based intervention for preschoolers with autism spectrum disorder. In *Frontiers in Education* (Vol. 4, p. 27). Frontiers.

Whitaker, P. (2007). Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say—and what parents want. *British Journal of Special Education*, *34*(3), 170-178.

Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising? *Mental retardation and developmental disabilities research reviews*, *8*(3), 151-161.

Wing, L. (1988). *Aspects of autism: Biological research*. Royal College of Psychiatrists.

Witwer, A. N., & Lecavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of autism and developmental disorders*, *38*(9), 1611-1624.

Wolbring, G. (2008). The politics of ableism. *Development*, *51*(2), 252-258.

Wong, J. D., Seltzer, M. M., Greenberg, J. S., Hong, J., Almeida, D. M., & Coe, C. L. (2012). Stressful life events and daily stressors affect awakening cortisol level in midlife mothers of individuals with autism spectrum disorders. *Aging & Mental Health*, *16*(8), 939-949.

Wong, C. C., Mak, W. W., & Liao, K. Y. H. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, *7*(6), 1385-1395.

Woods, M., Macklin, R., & Lewis, G. K. (2016). Researcher reflexivity: Exploring the impacts of CAQDAS use. *International Journal of Social Research Methodology*, *19*(4), 385-403.

World Bank, (2019). Data Statistics, data by country.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods*, *2*, 235-251.

Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American journal on intellectual and developmental disabilities*, *122*(1), 49-61.

Zaidman-Zait, A., Mirenda, P., Duku, E., Vaillancourt, T., Smith, I. M., Szatmari, P., ... & Zwaigenbaum, L. (2017). Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. *Autism*, *21*(2), 155-166.

Zuna, N., Gràcia, M., Haring, S. H., & Aguilar, J. M. (2016). Parental perceptions and satisfaction with family services in families of children with autism spectrum disorder and other developmental disabilities. *Journal of Intellectual & Developmental Disability*, *41*(3), 233-242.

Zweers, I., Bijstra, J. O., de Castro, B. O., Tick, N. T., & van de Schoot, R. A. (2019). Which school for whom? Placement choices for inclusion or exclusion of Dutch students with social, emotional, and behavioral difficulties in primary education. *School Psychology Review*, *48*(1), 46-67.

Appendices

Appendix one: Brief report on the way of accessing participants

Date	Initial method of communication	Number contacted	Selection method	Initial response numbers	Number emailed with details, consent forms and prompts	Number of received stories	Notes
7 Jan	Whatsapp by the Oman Autism community	97	The one they have records of them	5	4	3 stories 1 demographic data	She said she was interested but never responded
15 Jan	What's app	20	First 20 in what's app group by alphabetical order	9 with interest* 7 agreed to participate	7	5	*2 said they needed to consult their husbands and did not respond again Reminder sent to 2 mothers 26-1-18
21 Jan	What's app	20	Last 20 in what's app group by alphabetical order	11 with interest 5 agreed to participate	5	3	Reminder sent to 2 mothers 26-1-18
26 Jan	What's app	20	The next 20 from the alphabetical order	14 with interest 9 agreed to participate	9	5	
30 Jan						3	
1 Feb				5 agreed to participate	3 sent their emails	2	A reminder was sent to some ladies

					2 never responded		from previous groups
2- 6 Feb						4 stories	2 ladies sent their demographic but never sent their data
Totals		**157**		**34 with interest 27agreed to participate**	**30**	**25 (I did not count the 2 demographic data)**	

	Audio recorded	**Written**	**Photos or emails**	**Total number of stories received**
As at 30-1-18	4 recorded 1 youtube video 1. 28.27 m 2. 22.77 m 3. 14.00 m 4. youtube video 15.19 5. 6.41 Transcription is done for all of them	12 two stories in English 1. 2428 words 2. 1939 words) Arabic stories 1. (15 pgs. turned to be 2060 words, she sent them as photos and I wrote them in the computer) 2. 337 words 3. 409 words 4. 533 words 5. 1174 words 6. 885 words 7. 372 words 8. 1440 words 9. 371 words 10. 213 words 11. 576 words 12. 290 words 13. 439 words 14. 1767 words	6 stories sent to me via email 14 as a photo through whatsapp (they printed and wrote their stories, but could not scan them)	25 (1 without demographic) (2 demographic without stories, but I will stop)

		15. 302 words 16. 860 words 17. 647 words 18. 435 words		
TOTALS	**5**	**20**	**25**	**25**

Different Responses I received

1. We wish you all the best
2. Never replied
3. Not interested
4. I will consult my husband
5. I am interested (but never responded back like sending their emails)
6. Sent their emails to me and I sent the consent and information sheet to them, but never heard back from them
7. Some they asked for help as if I am specialist (but not interested in my research)
8. One lady turned to be a head-teacher at a special school for children with ASD
9. One lady has two children who are not ASD, they have cerebral palsy
10. A lady, her daughter has Rett Syndrome

Appendix two: Interview question guide

Would you please tell: What does the word "education" mean in relation to your child with ASD?	How do you describe his/ her education at this stage
Please explain what led you to educate your child with an ASD in the way that you have described in your story?	
You have mentioned several therapies you have chosen for your son/daughter, what were the factors that encouraged you choose these? How did you find out about them?	Therapies such are (diet therapy, functional therapies, speech therapies, finding a centre/ school/ specialist)
Describe some of the decisions you have made regarding the education of your child	Do you think these decisions where successful?
Is there any difference to what you think of as 'education' for your child with autism compared with your other children or for other children in general?	Why or why not?
Describe what you feel the best practice) for your child.	What would it include?
What do you understand the term 'Autism' to mean? Has your understanding of this term changed over time?	
Please describe a typical school day for you and your child with autism.	
Please describe a typical weekend/ holiday for you, your child with autism and your family.	
Is cost of education important in your decision making?	Why/why not?
Can you tell me about some of your experiences when trying to enroll your child in school?	Did your way of dealing with enrolment change over time?
How have you dealt with transition from one school to another?	
Upon reflection, would you have changed any of the choices that you made?	Why were these ways chosen? How do they operate? How successful have they been?
Over the years how have you dealt with the problems that have arisen with the way your child has been taught?	
Were any changes made to the course content? If so, how were these decisions reached?	How did your child respond to such changes?
Have you been consulted about how your child is taught and what is included in their courses of study?	If so, how useful was such consultation?
Do you feel the specialists have appropriate training when trying to educate your child?	What do you see as appropriate? How successful has the process of inclusion been for your child?

	What could you suggest that would help to improve the situation?
Have you accessed Ministry of Social Development/ Ministry of education services for children with autism?	How? If so, how successful were they for your child?
Is there one single way of doing things that you have found which works best when trying to educate your child?	Or have you found that a variety of ways of doing things has been more helpful. Please explain.
What factors helped you to work out these successful ways of doing things?	
At what stage of your child's education did you feel the most prepared in your decision-making?	Why?
Have you felt isolated while trying to educate your child?	What have you done to deal with this isolation?
Is there anything in your background (gender, education, career, strong family life and so on) which you feel has helped you deal with the education of your child?	
You mentioned that you belong to a whatsapp group, which links you to other mothers who have a child with an ASD? Have these links been useful? Please, explain	What has been the best help this group have given you?
Have there been any significant teacher/specialist who have helped?	Please explain who they have been and what they did.
What do you think has been the most difficult thing about trying to educate your child with an ASD and the other children in your family?	How have you dealt with this?
If you could speak to a mother of newly diagnosed children with an ASD what would you advise them?	Why are such things important?
What sort of support do you feel is needed for parents trying to educate a child with an ASD?	Why is this support necessary?
Has your level of involvement with your child's education changed over time?	If so, what are the reasons for this change?
Has your ability to deal with the educational challenges of your son/daughter improved over time? How important are ministry of social development and ministry of education when it comes to helping families deal successfully with their children with ASD?	Why/why not?
How do you see your level of involvement with your child in the future?	
What are your hopes for the future for you child	
What concerns do you mostly think about with regards your child's present and future	

Please take some time to tell me anything else you would like to share with me that you have not had the chance to do so already.	

Appendix three: Examples of participants' story narration (all the names are psydonm)

1. Rahaf wrote her story in Arabic (and translated into English)

Mansoor is the fourth among his siblings and he was born naturally. His early growth was also 'normal'. His communication skills were very natural in the first months of his life, but he had delay in his speech. I had concerns about the delay in his speech, but everyone responded that this was very normal and there was no need to worry. Why did my son not yet talk? The answer from everyone was: "This is normal and there are many children who have delay in their speech." Mansoor completed his second year of life and did not yet utter a word. I also began to notice that he was losing his skills in communicating with us. Whenever I called him – 'Mansoor, Mansoor, Mansoor'– he never paid attention. I started to think. I thought that he might be suffering from a hearing problem. I immediately took him to the GP and explained his problem to them. The doctor assured me that my child was developing typically. Mansoor remained in the same situation for a while, and he never paid attention and became a very calm person. The questions came to me again, therefore I took him to an otolaryngologist who examined his hearing and assured me once again that Mansoor was normal. So, why he did not talk? Why was this happening to my son? Why did he not pay attention when I called him by his name or spoke to him? The doctor advised me to take Mansoor to another doctor, to find out if he was suffering from another problem. I actually took him to a speech specialist. On our first visit, after a very short time and after several exercises the doctor carried out with Mansoor, he told me that my son suffered from a disorder that causes children to lose their ability to speak. This disorder that causes children to lose their ability to communicate with the community is called autism. I was very shocked and did not understand anything the doctor said. The only thing I managed to say with difficulty was: "This means that my son will never speak." The doctor's answer was that the symptoms of autism did not completely disappear from the person, but perhaps his condition would improve with treatment and continuous training. Autism was a new term that I had never heard of, so I began to search for the meaning of autism and its symptoms and the methods of treatment. I found out that autism is a very large and mysterious world: how would I be able to treat my son? Which countries in the whole world had been able to treat autism? Many questions were in my mind, with no answers. I started taking him to many centres and many hospitals to find a solution for my son and find a cure for the so-called autism. I told myself that I would not leave my son in this situation; that's what I said to myself, until one of the sisters introduced me – God bless her – to a group of mothers with children suffering from this disorder, to varying degrees. I found autism a really huge, deep, and different world. Mothers were very welcoming and kind, and they made me feel how special I was as a mother of child with autism. They helped me to believe that my child would improve, but he needed time, effort, and patience. I felt that I was special to have this

little angel who would lead me with his hands to heaven.
A great dose of hope given to me, I then felt comfort and tranquility. Honestly, it took me a long time to overcome my problem, but then I decided to start a new life and to be strong and receptive to the grace of God. I tried hard to help my son and fight for him. I started with my family, and then my mother, brothers, and sisters, and then the community around me. I told everyone that my child would become a 'normal' child but that he needed love and attention. My family members accepted the situation and took some responsibility for Mansoor, and I cannot forget that my mother has been helpful and Mansoor is her main focus of attention and care. She has had endless attempts in teaching him to repeat words after her. I noticed that everyone started to love and care about Mansoor. They never got annoyed with him, though he really broke everything around him because of his hyperactivity and his lack of self-consciousness. Our lives have changed. Mansoor is growing up, and my responsibility grows every day. I become more fearful for him because he does not recognise dangers; he does not differentiate between right and wrong.

The only thing that I focused on was raising everyone's awareness that my child is very 'normal' but he needs a lot of attention; to deal with him as a 'normal' child in the way he is talked to and in all daily activities; to be punished if he makes mistakes and to be rewarded if he responds to any order, even if it is very simple. I heard that there are rehabilitation centres in the area where I live, so I went to one of them. They did some simple tests for Mansoor, to know exactly what he needs and know his strengths and weaknesses. Mansoor has received daily training to strengthen his visual and social communication, and other, skills. I like the cooperation from the specialist of the centre and their interest in the child, and they keep asking about him and his behaviour. I do not forget their great help to overcome the problem of Mansoor sleeping, which we suffered on a daily basis. We stayed awake all night through to the morning, and we went to our jobs, and we were very exhausted. But that's not enough: our children need more attention from the government, and rehabilitation should be better. There is a need for more experts in the area of autism, so everyone can overcome this nightmare. Everyone knows that inside children with autism, there is intelligence, strength, and geniuses if they get the correct rehabilitation and training. So, why don't children with autism get what helps them to get out of the autism circle? Why don't we try to save society from this problem? I can never hide my great fear for my son and his future, after many endless attempts of daily exercises in the centre in the mornings and at home in the evening. In addition to that, we specify leisure time with his father and brother to help Mansoor, and thankfully, he has improved greatly in his communication skills. Mansoor is now seven years old, and we still have the same programme for him, and we give him a lot of orders. We also deal with him in a very natural way. Though there are times that I feel tired and stressed, I try to gather strength, so I do not collapse. Mansoor is now coping well with other children at playtime, and he is no longer closed in on himself. He responds to anyone calling his name. He tries to depend on himself to drink, eat, and wear clothes, to some extent. We are still continuing with the training, in the hope that he will at least reach the stage of relying on himself and be aware of danger.

I wish the decision makers would pay more attention to our children and their education and their rehabilitation. I see that there is a lack of training and rehabilitation in my country. Unfortunately, this training and rehabilitation do not help children with autism to change in a tangible way, but if they find the attention and care they need, they may be great people in the future.

I only have prayers to the Almighty to grant me the strength, patience, and ability to endure the next stage with my child, and to thank everyone who has been with me on my journey with autism.

2. Zulfa recorded her story in Arabic (and translated into English)

I am a mother of a child with ASD and I discovered that my child had autism at the age of six months. Of course, I doubted his behaviour before he was six months old as he was unlike other children. I mean, he was not crying, or he did not want me eagerly. He did not have eye contact with us. He was not growling or grunting, and he never missed me. I never felt that he knew that I was his mother, because he was never happy when he saw me, or he cried wanting me. Anyone could take him instead of me; it was totally normal for him. It was not normal, of course. When he was six months old, I really started to doubt that he was not a normal childlike his brothers. I doubted that, because his visual skills were completely non-existent. He was not growling and was never saying Mama nor Dada and other words. He was unlike the rest of the children who were uttering some words at his age. The months went by, and I waited patiently. I never knew what he was suffering from. I did not understand anything until he was one year old. I decided that now, it was time for me to understand my child and what he had. I went to the nearby health centre and, of course, the health centre assured me that my child was normal, and his speech delay could happen to many children, especially boys. I returned home and I was not convinced of their words. I just wanted to know what my son had. I waited for two weeks, and once again, I went back to the health centre and complained about the symptoms I was exposed to, which was the lack of communication and uttering sounds. He never felt that I was his mother and he never paid attention. They said the same thing, to give him more time. I went back home, and I was confused and worried. There was something unusual but I did not understand it, and I went back to the health centre once again and explained to them his symptoms, and again they said to give him time. I waited till he was 13 months old, and this time I decided to take a final decision. I told them that I had had other children and if my child turned to be unlike his peers, they would be fully responsible for his delay. This was my third time going to the centre, and I knew that he was not like the rest of his siblings I had raised before him. They suspected that he had a problem with his tongue, which was preventing him for speaking, but he did not have this problem. They checked his hearing, and everything was fine. They started to doubt that the child was physically normal, so this time they tried to do something for him, and they referred me to the main hospital. We were referred to the pediatrician in the main hospital and looked through the reports written about him, and she decided to tell us that all the symptoms my son had were symptoms of autism. And of course, I was shocked, and I started to shout at her. I said no, my son did not have autism. She responded: what did I know about autism? I told her that a child isolated himself away from other children and never played with them. She told me that my information about autism was weak. Autism was not only displayed by being isolated from others, and she started explaining to me the characteristics of autism. I could see that what she was explaining matched my child's symptoms. I was not comfortable, and I was shocked, and I isolated myself from others and I spent days crying. I decided that I needed to help my son, and I went back to the pediatrician. They took the first step of referring me to a specialist in the main hospital. There, they told me that they could only start speech therapy when he had a diagnosis, which meant I had to wait for a year and two months, doing nothing. I needed to wait until the diagnosis was done, which was frankly a great inconvenience. I felt I was losing a year and two months of my son's life. And I had to waste a year and two months in vain, which annoyed me greatly. I did not feel that I could wait, and frankly, I began to take him to sessions using the Holy Quran, and those were at my own expense. When I was taking him to sessions, I met a mother of a child with autism. She asked me a lot about my son, and she provided me with a lot of information about autism. She also told me about a group of mothers who had formed in order to share information and support each other. I did join that group, and we shared experiences about our children. In this group, we helped each other to feel comfortable and happy. I felt stressed before I joined this group, but the stress was reduced as I got along with them. In addition to that, my husband and I were looking for information about autism, and we knew more through our searching, and joining the group enriched my knowledge about autism.

I knew through the group that there was a specialist in autism, and we decided to take an appointment with this doctor. We went to him and began the first steps for treatment. The doctor thought that there were some tests that should be done for my son. These tests were sent to Germany and cost us 240 Omani rials. We had another appointment with the doctor after he received the results of the tests. The report confirmed that our son had the symptoms of autism and the food that our son was eating had caused fungus in his stomach, which had an effect on his brain. So, the first step was to stop feeding him this food. So, we started diet therapy, which meant he should stop eating dairy products, such as cheese or yogurt. We replaced white flour with whole meal flour; chicken eggs with quail eggs; white sugar with brown sugar; and cow's milk with camel milk. We had an agreement with certain supermarkets to provide these things for us, such as to provide us with three cans of milk from France a month. We continued with the diet therapy, and after two months of diet, our son began to pronounce his first letter; he was almost a year and three months. My husband and I bought some books for our son. We selected sound books that pronounce the character. So, our child started echoing these books; we spent time with him doing and following these things. We also bought some puzzles for him and, of course, we were seeing the doctor every month. He prescribed some food supplements, such as Omega 3. We continued using the sound books with him and prevented him from watching television, and we gave him the Omega 3 supplements. We struggled to give him the Omega 3. We started by giving him the supplement in the juice (fresh juice, of course). The doctor ensured to give him fresh juice and he was taking it for a while, but later he thought that there was something wrong with the juice, and he stopped taking it. So, we gave him the Omega 3 with a spoon, and I had to force him to take it. This was very exhausting, and the child did not understand us. We had to lock the doors all the time and we had to replace all the locks more than once; it cost us a lot of money. If he went out, he never knew the way back home. He was not responding to us; he was like a statue in the house. He never knew how to say my name or the name of his father. In fact, he did not know that I was his mother, and he never knew his father. But we continued with the sessions, the supplements, and the diet therapy until the diagnosis appointment. The doctor in the main hospital diagnosed him as being on the autism spectrum. Of course, this made me annoyed and upset. I told the doctor that I had known my son’s diagnosis; I would not wait 14 months for her diagnosis; and she said that she was sorry, but she was the only autism specialist in the whole country. She referred us to another government hospital, so we could start the speech therapy sessions. We also asked for functional therapy sessions in the hospital. So, he had two speech therapy sessions and one behaviour therapy session per week. This was a real struggle for me. When I parked the car, my son would open the door and run into the street. So, I had to run after him, in front of people staring at us. There were many times he was running, and I was suffering. I felt humiliated and fatigued. As soon as I went back home, I cried. We continued with the speech therapy in the main hospital until we discovered that new private centres had opened. So, I decided to increase the sessions in these centres. Once, I attended a symposium about autism in an institution, and there, mothers told me that I could treat my son without paying the fees, but I needed to make an ID card for him. This card is used for disabled children. This annoyed me hysterically, and I shouted, telling them my son was not disabled. I was shocked and disappointed, and I cried for a long time. But we decided to go to the Ministry of Social Development so we could make this ID card, in order for the ministry to pay the fees to treat him in the centres. We did that because the sessions were expensive in private centres, and we willingly accepted for this card to be made. They said that they would issue this ID card, stating that he was a child with a disability. Frankly, the word ‘disability’ had a strong effect on me and caused me pain that I even cannot describe. I told them that I did not want that card, because my son was not disabled. I just left them, and we continued to pay for his sessions at our own expense. After that, I suggested to my husband that we use comprehensive medical insurance from my husband's job, which would help us pay for our children's medical treatment and ourselves. So, my husband went to the doctor in the clinic at his job and applied for financial help to pay the fees. He told the doctor that our son was on the autism spectrum. But the doctor refused the application form because he did not believe in something called autism. We requested them to at least pay for the supplements, and again, the doctor refused. So, we continued paying for his treatment at our own expense. The centre was exploiting us. For example, they once told us that there would be a visiting doctor and a specialist who could help us, but we had to pay. We paid 60 rials. The doctor sat with the boy for only half an hour and told us that our son was 'normal'. I told him: yes, our child is 'normal', and we had a lot of money, so we spent this everywhere, with no reason. I just wanted him to know that we had been spending a lot of money on treating our son in vain. I spent 60 rials, without any benefit.

Once again, the centre told us that there would be a doctor who specialised in brain problems, and we had to pay 20 rials in order to book an appointment with him. We did book an appointment because we had doubts that our son had a problem in his brain. Again, the doctor did nothing, just looking at him and saying he had nothing to worry about. These were some examples of exploitation in the private centres. We felt that there was a lot of expense we had to pay; we felt exploited, and we were exhausted because of all this. The time passed, continuing the session in the main hospital, and in the centre, we noticed that he had started to slowly improve. He started uttering some words and letters. The child was almost three years old, and he was saying some simple words. I thought of enrolling him in a school teaching the Quran, so he could be integrated with the children, because the doctor said integration with children would help his development. The Quran school took him for a short time, but later, they refused to accept him. I knew that my neighbour was taking children to teach them at her house. I asked her if she could take him as well so he could be integrated with other kids, and that I would pay her monthly. Again, she refused to accept him among the other children. So, I decided to take him to a nursery, and I hired a driver for 20 rials, and I spent 30 rials on the nursery. He stayed in this nursery for almost a year, and the child seemed to improve gradually.

The child started to be integrated with other children, but unfortunately, the head teacher of the nursery called me and told me that they did not want my son. I asked her why, and she said that my son seemed not to get along with the children. This really annoyed me because my son did not cause any problems. Why did not they want him? She said that I had to find the right place for my son. I started crying and I was tired. I spent the whole day crying and feeling depressed. I asked everyone and looked everywhere, but my son was at home. Yes: I was taking him to the session in the evenings, but he spent mornings at home, so I had to find another option.

My neighbour told me that a nursery had opened, but this nursery was really far away from us. This nursery had the hour system, so a child stays with them per hour. I took my son, and we went to them; I said I would try this one. They accepted him and told me that he would stay with them just for two hours. Every day I took him to the nursery, and I waited for him under the sun and in very hot weather. Then, I paid the amount of money for these two hours, and I went back home. Every day was a struggle for me, because the nursery was far away from our house and he was hyperactive when I was driving, and several times, he opened the doors. I had been in this situation every day in order to help my son, so he could be integrated with other kids. But I insisted that I would do whatever I could do. I never gave up anything I was capable of. At the same time, I was asking about schools that would accept children with autism. I had heard that there was a school for these cases such as children with Down syndrome, and children who had speech delay and learning difficulties, and other conditions. It was a private school that had a special section for children with special needs. I told myself: why not try it? At that time, the boy was not able to go to the toilet by himself. He even was not able to wear his shoes independently. They agreed to help me, but the fees were very expensive. I had to pay 2,000 rials per year, but they were kind and considerate and reduced the fees to 1,600 rials per year. I told them that I had other expenses to pay, such as the evening sessions and the supplements. So, they honestly reduced the amount of fees. We continued with this school, the evening sessions, and the sessions in the main hospital, as well as the supplements I was giving to him. He began to change; his perception became better, and his behaviour changed. He started to depend on himself, and my son seemed to change greatly. He continued with supplements for three years in the school, and the child changed and depended on himself. When he was five years old, he seemed to utter simple sentences of two or three words.

My husband’s work agreed to pay for the private centre, and we continued paying for the school. The boy, as I said, had improved greatly, so the school decided to take him out of the special needs department and integrate him with other children, because he became like the other typically growing children. He seemed to read and started writing, so they registered him in the reception class. In addition to that, they provided him with behaviour and speech sessions. But again, we felt that the school was exploiting us, because they refused to reduce the amount of school fees. Since our son started to be in the mainstream classes, then according to the school rules, we should pay less. But the school wanted to keep the same amount of fees.

We, the parents, were requesting the government to integrate our children in the mainstream classes into the government schools. The ministry told us that they had been studying the practicality of integration with the students who could be integrated. The Ministry of Education, with the cooperation of the Ministry of Social Development, had to test children with autism and decide who would be able to be integrated in the mainstream classes. My son, thank God, managed to be similar to his peers, who were growing typically. They tested him and he passed their test, but they told me that it would be better for him to be in a private school. I asked them why they would not accept him, because he was capable and independent. They said no, his abilities were below expectations. They insisted he be kept in the reception class and not in year 1, and we paid 1,600 rials. I frankly felt annoyed with their behaviour, so I decided to register him in another school, but a private school.

I took him to a private school and asked them if it was possible to evaluate my son so he could be in year 1. I told the school that my son had speech problems, but I never told them that he was a child with autism. They evaluated him and decided to enroll him in year 1. He is a typical child, like his peers. He is able to read and write. He has a speech problem, but we are doing our best to overcome this.

I mean that most of the autism characteristics disappeared. This happened by using the supplements and diet therapy at home, by integrating him into the society. Thank God, the child began to become a typical child. He is still a hyperactive child, but I still take him to the session in the private centre and the session in the main hospital. He is now in year 2, and I have started to buy books for him, chat with him, and discuss the topic with him. I usually sit with him to discuss different topics. I also give him instructions at home, such as: bring this from there. I also take him to the shops with me, and there, I tell him about different things. I start with a word, and then add another word to it. In this way, I taught him shapes and colours. For example, I tell him this is a banana, then I add a yellow banana, and so on. I insist on repeating these phrases to him; though he is not speaking, he is retaining words. When we go back home, I ask him: where did we go and what did we do? When we go shopping, we keep talking to him. Though he was not saying anything, he was storing. After a while, he started responding to me and to my orders.

After he responded to my instructions I moved to a second stage, which is asking him about what he did and why he did it. Instead of receiving the orders, I wanted him to think and talk about the instructions. The questions and answers helped him. Now, he initiates questions. For example, when he comes back from school, he asks me: Mama, what are you cooking; where are we going; or what are you doing? The last time we were in the main hospital, the doctor told us that he is now in the last stage of his sessions, which is the stage of dialogue with him. And he is becoming a 100 % typical child in my point of view.

3. Maha produced a YouTube video (and translated into English)

My story with Jamal started with pregnancy, and I had many problems during pregnancy, including a high temperature. When I went to the doctor, they insisted I stay in the hospital for a while, because the fever infected the child. The birth of a child is usually difficult, but the birth of Jamal was even more difficult than any other child. When Jamal was born, he was not breathing and he was suffocating, but thankfully, he survived. In his first early months, I noticed that Jamal was not totally normal and he was mostly inert or inactive. He was always sleepy; he did not respond; and he feared loud voices. I felt that he was not a "normal" child. On one hand, he was not responding and his responses were delayed if I called him. As the days passed, I noticed that he became even calmer. Children at his age respond to us. I mean, he was not playing like children who were at his age – three or four months. Children at this age accept that you speak to them, and they spontaneously respond to you. But Jamal was unlike them. He was upset by noises and closed his ears, and he did not have eye contact.

My relatives and my friends asked us about Jamal's problem whenever they saw him. They always asked why he was like this, what was wrong with him, why did he not play with others and play alone. We faced many spontaneous diagnoses from people and relatives, including those who told us that he might have an evil spirit. There were people who said that it was possible that he had had a certain disease. I am not against evil spirits, but I am against associating every weird thing to evil. So, I did not give in to these things people were saying. As a first step, my husband and I decided to take him to a doctor, and the doctor was the one who could diagnose him. Perhaps we could get an answer. We actually took him to a doctor in a hospital in our town. The doctor examined his hearing and vision. Everything was 'normal' for a child at his age, and at that time, he was 18 months old. We had been told that maybe his condition was related to psychology and could be reviewed by specialists of psychology (psychiatric). So, we were transferred to the main hospital in Muscat (the capital city). We took him there when he was almost 18 months old. The doctor told us that he might have autism spectrum disorder (ASD), but he said it was difficult to decide on a diagnosis at this age. When the child reached the age of two and a half or three years, it was the appropriate time to confirm the diagnosis. So, diagnosis could only be confirmed when he was a bit older. We did not know anything called autism, and we had never known any thing like that. We heard the word 'autism' for the first time from the doctor. We tried to look for this, and frankly, it was the first time we heard about autism. When Jamal was two years and eight months old, we went to our appointment in the main hospital and we met the doctor. The doctor examined Jamal's ears and eyes, to make sure whether Jamal had the diagnosis of autism or not, and he confirmed that Jamal had autism. We were shocked and we did not expect that. We had hoped that the doctor would say something comforting, but this diagnosis was confirmed by the doctor. At home, we were struggling with Jamal, as he was always running, jumping, and fluttering with his hands, and sometimes shouting and crying without a reason. His sleep was not for long periods, and his sleep was not comfortable. He could not play with children, or he did not play with them in an appropriate way. There were other problems, such as if I was trying to go out and I got distracted for a few seconds, he would jump into the car and he would lock all the doors.

But I noticed that he needed to be talked to quietly and he would never accept me shouting at him; this would make him scared. Jamal was always running out of the house, midday or midnight. Sometimes, we found him in our neighbours' homes, or we found him locked in one of our cars. Once we found him in the middle of the road spinning, and people around him did not know what he was doing. Luckily, he was not killed in any of these cases. No matter how we describe the suffering we were experiencing with him, no one can understand it except those who are going through a similar situation.

After diagnosis

The first step we took after diagnosis was self-education. Our self-education meant how to deal with Jamal. We tried to make our relatives understand that Jamal was a child with autism, but they did not know the meaning of autism. So, we tried to explain to them the meaning of autism. We discovered that there were other families who were in a similar situation. So, we met a special group who cared about autism. In this group, there were many mothers who spoke about their children with autism and their behaviour at home, and how they faced their problems. There was cooperation between these mothers, in order to reduce burden on them.

The journey of therapy

After we heard the diagnosis from the doctor at the hospital, we felt that was not enough and we were not satisfied. We still hoped that the diagnosis was wrong. We tried to ask about private clinics, and we actually found a special clinic specialising in children with autism or an autism disorder. We immediately took Jamal to the doctor, and he checked him and confirmed that Jamal was 100% on the autism spectrum disorder. So, he recommended some treatments, and one of the treatments was diet therapy. The idea of diet therapy is that we prevent him from eating regular food, and that we give him special food. This was not easy for us, especially as we are from a low-income family, and food and medicine were very expensive. The food quantity was little and its consumption was fast.

The education journey

A private school was the only option in front of us at that time, and there were not many. In addition to that, we could not afford it, and educating him in such a school was very expensive. So, we went to the institutions that were responsible for the education of our son, and we were advised to take him to a public centre for children with special needs in our town. We tried to send him to a private school even at our expense, at least at nursery level. We went to almost all of these schools, but they all rejected him. A year or more passed, and we found out that a special centre for children with special needs in our town had been developed. This was remarkable, and a lot of work had been done at this centre. We noticed their care towards our son, and in many cases, they taught him things voluntarily. They never had external funding though, so sometimes it was difficult for things be done for him. All those who were working in the centre were hard-working people who cared about Jamal as if he were the only child who was studying at the centre.

The role of the family

We tried to deal with Jamal as a child with autism at the same time as trying to deal with him as a ‘normal’ (typically growing) child. We combined the two things and tried to balance between the two, so we could understand him and enter his world, as well as he tried to understand us. We tried to educate ourselves how to deal with Jamal, and tried to teach him reading and writing.

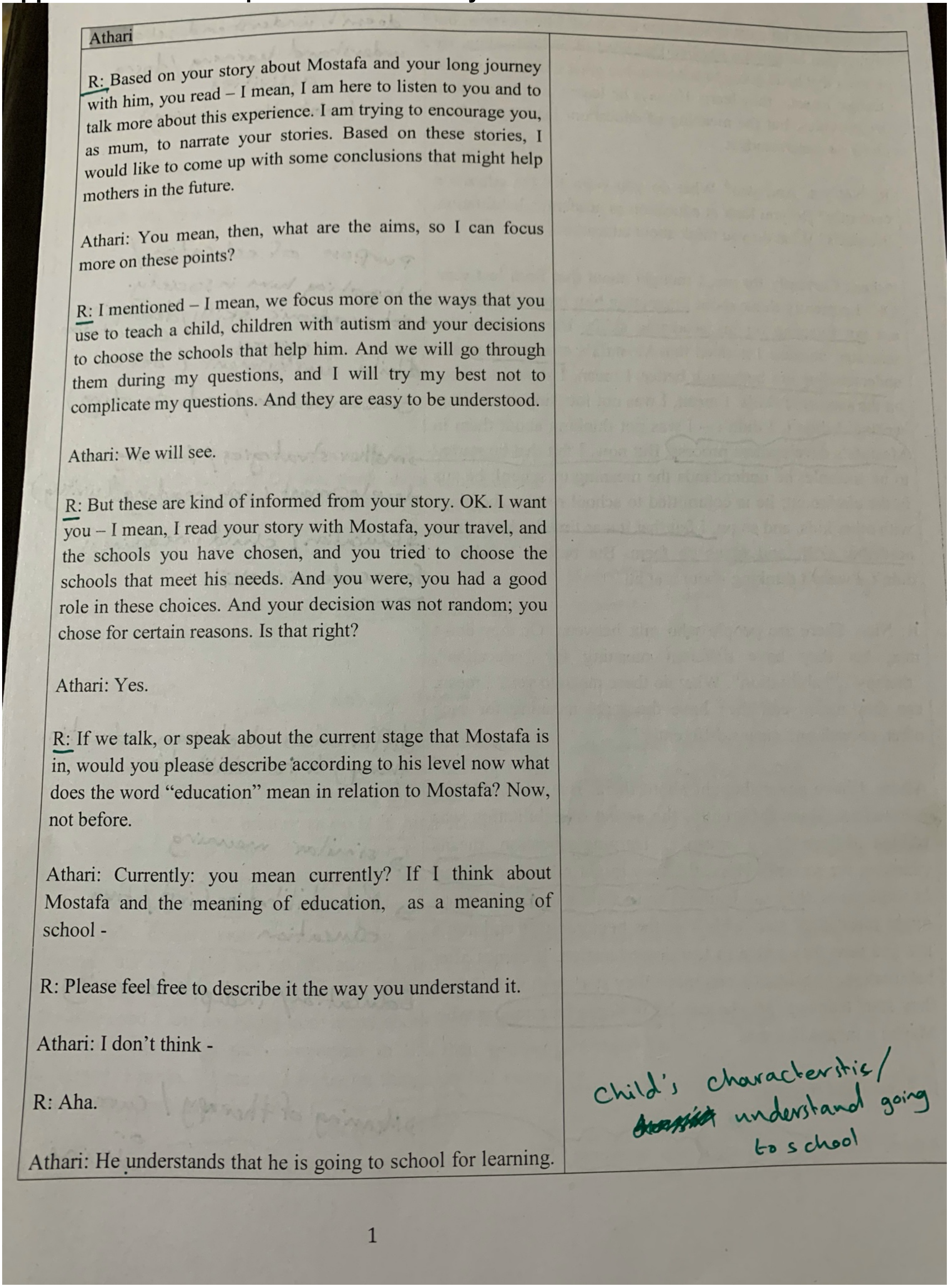
In fact, Jamal is a clever boy. I know my son very well. Jamal’s concentration and memorisation are really good, and he retains and never forgets things he learns. He has the capabilities and abilities, but the problem is that these abilities are not used and developed appropriately. At least we are looking for the tools that are necessary to use these capabilities and abilities. We need help to develop Jamal, and if he does not get the needed help and support, he will never progress.

My advice to families who have a child with autism is to be patient with him/her and to treat him/her ‘normally’. At the same time, they should be considerate because the child has a special situation, needs attention and love, and s/he needs understanding, because s/he is trying hard to adapt herself/himself to the world.

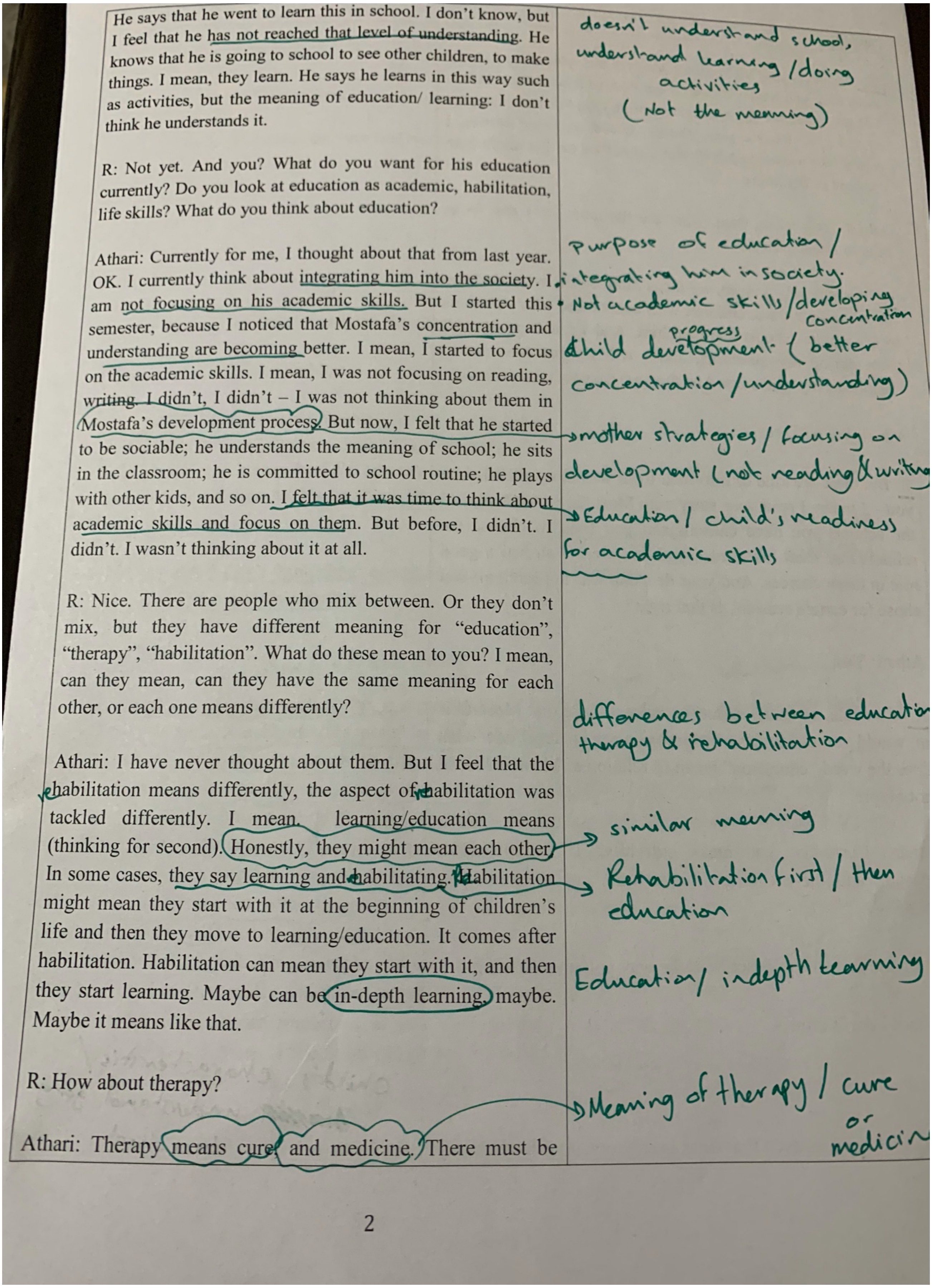
I do not care how important my son is to the country, but we have seen what the country has given to this boy. I do not care about people staring at my son. I do not teach my son to demolish, but I teach him how to build. Jamal and children with autism taught us how to love our children at any time and anywhere. They taught us not to feel shamed or bored. They taught us that they are everything to us and that we are everything to them. So, we feel that they are proud of us without saying so; and they do not love because we are spoiling them, but because they feel beloved and safe. They taught us not to concentrate mainly on changing them to be typical children, but to be proud of them as they are.

In conclusion, my son Jamal is not alone as we, and those who love him, are with him, and he knows that.

Appendix four: Example of interview Analysis

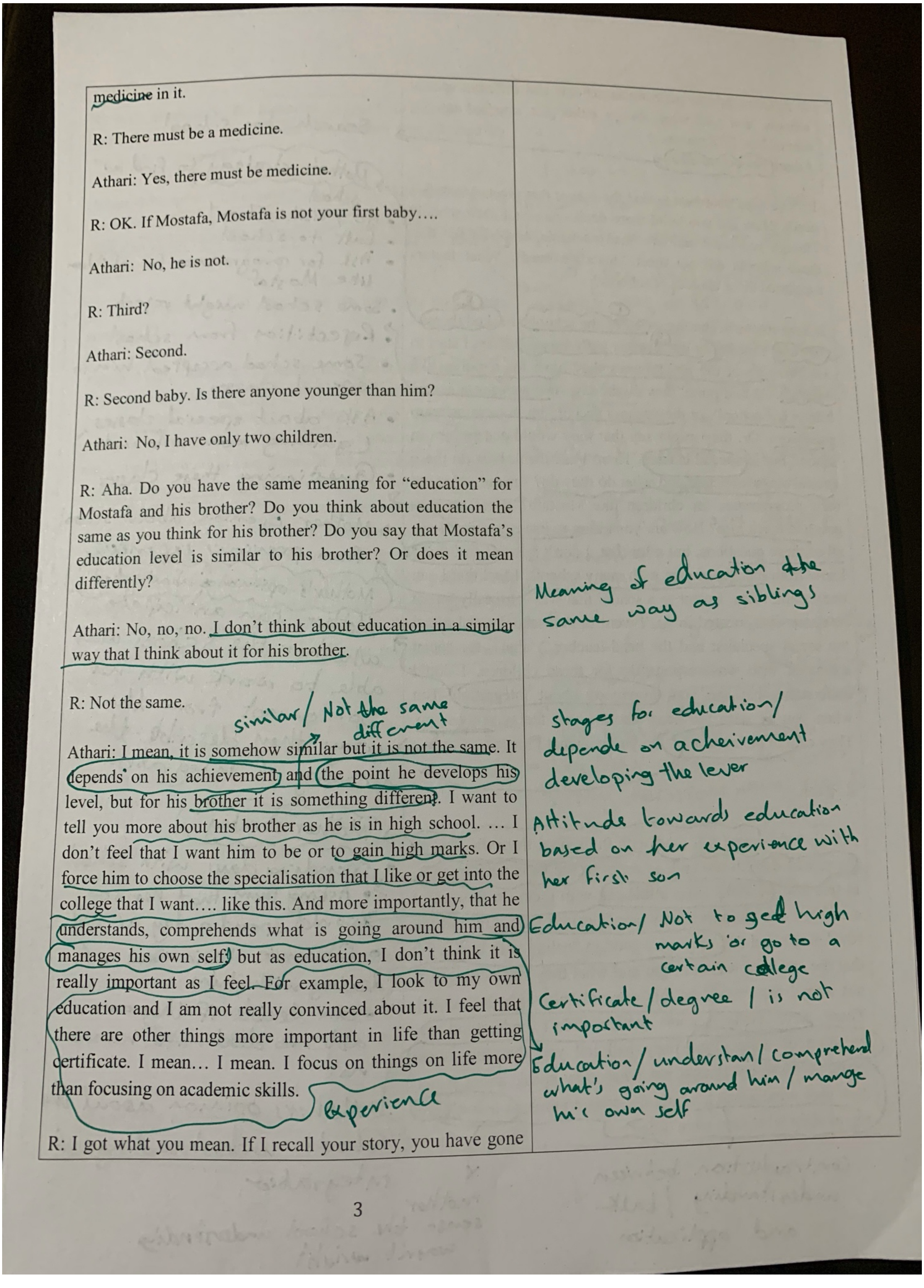


Athari	
R: Based on your story about Mostafa and your long journey with him, you read – I mean, I am here to listen to you and to talk more about this experience. I am trying to encourage you, as mum, to narrate your stories. Based on these stories, I would like to come up with some conclusions that might help mothers in the future. Athari: You mean, then, what are the aims, so I can focus more on these points? R: I mentioned – I mean, we focus more on the ways that you use to teach a child, children with autism and your decisions to choose the schools that help him. And we will go through them during my questions, and I will try my best not to complicate my questions. And they are easy to be understood. Athari: We will see. R: But these are kind of informed from your story. OK. I want you – I mean, I read your story with Mostafa, your travel, and the schools you have chosen, and you tried to choose the schools that meet his needs. And you were, you had a good role in these choices. And your decision was not random; you chose for certain reasons. Is that right? Athari: Yes. R: If we talk, or speak about the current stage that Mostafa is in, would you please describe according to his level now what does the word "education" mean in relation to Mostafa? Now, not before. Athari: Currently: you mean currently? If I think about Mostafa and the meaning of education, as a meaning of school - R: Please feel free to describe it the way you understand it. Athari: I don't think - R: Aha. Athari: He understands that he is going to school for learning.	Child's characteristic/ understand going to school



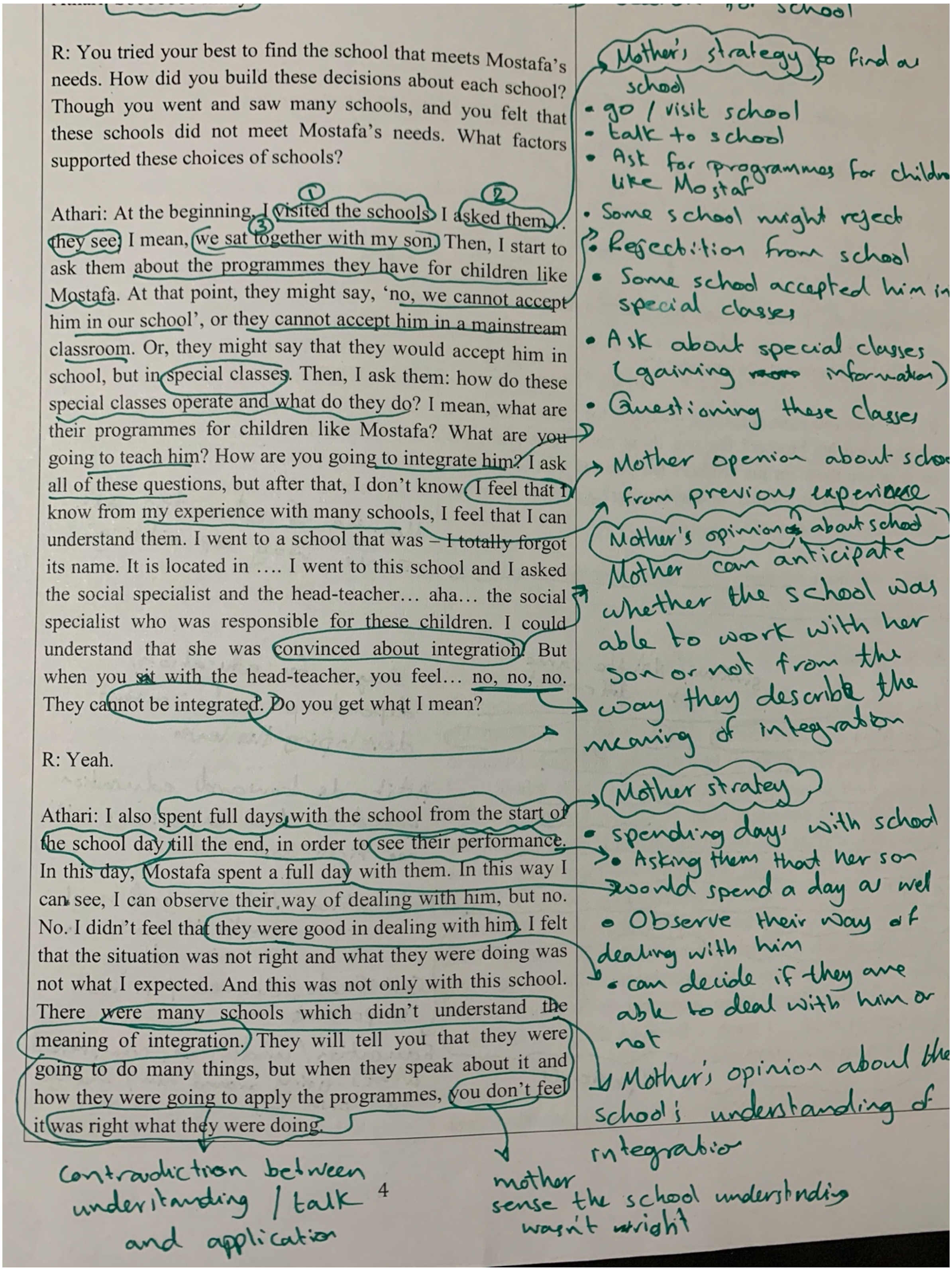
He says that he went to learn this in school. I don't know, but I feel that he has not reached that level of understanding. He knows that he is going to school to see other children, to make things. I mean, they learn. He says he learns in this way such as activities, but the meaning of education/ learning: I don't think he understands it.	doesn't understand school, understand learning /doing activities (Not the meaning)
R: Not yet. And you? What do you want for his education currently? Do you look at education as academic, habilitation, life skills? What do you think about education?	
Athari: Currently for me, I thought about that from last year. OK. I currently think about integrating him into the society. I am not focusing on his academic skills. But I started this semester, because I noticed that Mostafa's concentration and understanding are becoming better. I mean, I started to focus on the academic skills. I mean, I was not focusing on reading, writing. I didn't, I didn't – I was not thinking about them in Mostafa's development process. But now, I felt that he started to be sociable; he understands the meaning of school; he sits in the classroom; he is committed to school routine; he plays with other kids, and so on. I felt that it was time to think about academic skills and focus on them. But before, I didn't. I didn't. I wasn't thinking about it at all.	Purpose of education / • integrating him in society. • Not academic skills /developing concentration • child development progress (better concentration /understanding) → mother strategies / focusing on development (not reading & writing → Education / child's readiness for academic skills
R: Nice. There are people who mix between. Or they don't mix, but they have different meaning for "education", "therapy", "habilitation". What do these mean to you? I mean, can they mean, can they have the same meaning for each other, or each one means differently?	
Athari: I have never thought about them. But I feel that the habilitation means differently, the aspect of habilitation was tackled differently. I mean. learning/education means (thinking for second). Honestly, they might mean each other. In some cases, they say learning and habilitating. Habilitation might mean they start with it at the beginning of children's life and then they move to learning/education. It comes after habilitation. Habilitation can mean they start with it, and then they start learning. Maybe can be in-depth learning, maybe. Maybe it means like that.	differences between educatio therapy & rehabilitation → similar meaning → Rehabilitation first / then education Education / indepth learning
R: How about therapy?	
Athari: Therapy means cure and medicine. There must be	→ Meaning of therapy / cure or medicin

2



medicine in it.	
R: There must be a medicine.	
Athari: Yes, there must be medicine.	
R: OK. If Mostafa, Mostafa is not your first baby….	
Athari: No, he is not.	
R: Third?	
Athari: Second.	
R: Second baby. Is there anyone younger than him?	
Athari: No, I have only two children.	
R: Aha. Do you have the same meaning for "education" for Mostafa and his brother? Do you think about education the same as you think for his brother? Do you say that Mostafa's education level is similar to his brother? Or does it mean differently?	Meaning of education the same way as siblings
Athari: No, no, no. I don't think about education in a similar way that I think about it for his brother.	
R: Not the same.	
similar/ Not the same different Athari: I mean, it is somehow similar but it is not the same. It depends on his achievement and the point he develops his level, but for his brother it is something different. I want to tell you more about his brother as he is in high school. … I don't feel that I want him to be or to gain high marks. Or I force him to choose the specialisation that I like or get into the college that I want…. like this. And more importantly, that he understands, comprehends what is going around him and manages his own self but as education, I don't think it is really important as I feel. For example, I look to my own education and I am not really convinced about it. I feel that there are other things more important in life than getting certificate. I mean… I mean. I focus on things on life more than focusing on academic skills. Experience	stages for education/ depende on acheivement developing the lever Attitude towards education based on her experience with her first son Education/ Not to get high marks or go to a certain college Certificate/ degree / is not important Education/ understan/ comprehend what's going around him / mange his own self
R: I got what you mean. If I recall your story, you have gone	

3



R: You tried your best to find the school that meets Mostafa's needs. How did you build these decisions about each school? Though you went and saw many schools, and you felt that these schools did not meet Mostafa's needs. What factors supported these choices of schools?

Athari: At the beginning, I ① visited the schools ② I asked them… they see; I mean, ③ we sat together with my son. Then, I start to ask them about the programmes they have for children like Mostafa. At that point, they might say, 'no, we cannot accept him in our school', or they cannot accept him in a mainstream classroom. Or, they might say that they would accept him in school, but in special classes. Then, I ask them: how do these special classes operate and what do they do? I mean, what are their programmes for children like Mostafa? What are you going to teach him? How are you going to integrate him? I ask all of these questions, but after that, I don't know, I feel that I know from my experience with many schools, I feel that I can understand them. I went to a school that was – I totally forgot its name. It is located in …. I went to this school and I asked the social specialist and the head-teacher… aha… the social specialist who was responsible for these children. I could understand that she was convinced about integration. But when you sit with the head-teacher, you feel… no, no, no. They cannot be integrated. Do you get what I mean?

R: Yeah.

Athari: I also spent full days with the school from the start of the school day till the end, in order to see their performance. In this day, Mostafa spent a full day with them. In this way I can see, I can observe their way of dealing with him, but no. No. I didn't feel that they were good in dealing with him. I felt that the situation was not right and what they were doing was not what I expected. And this was not only with this school. There were many schools which didn't understand the meaning of integration. They will tell you that they were going to do many things, but when they speak about it and how they were going to apply the programmes, you don't feel it was right what they were doing.

4

Mother's strategy to find a school
- go / visit school
- talk to school
- Ask for programmes for childr like Mostaf
- Some school might reject
- Rejection from school
- Some school accepted him in special classes
- Ask about special classes (gaining ~~more~~ information)
- Questioning these classes

Mother opinion about scho from previous experience

Mother's opinions about school

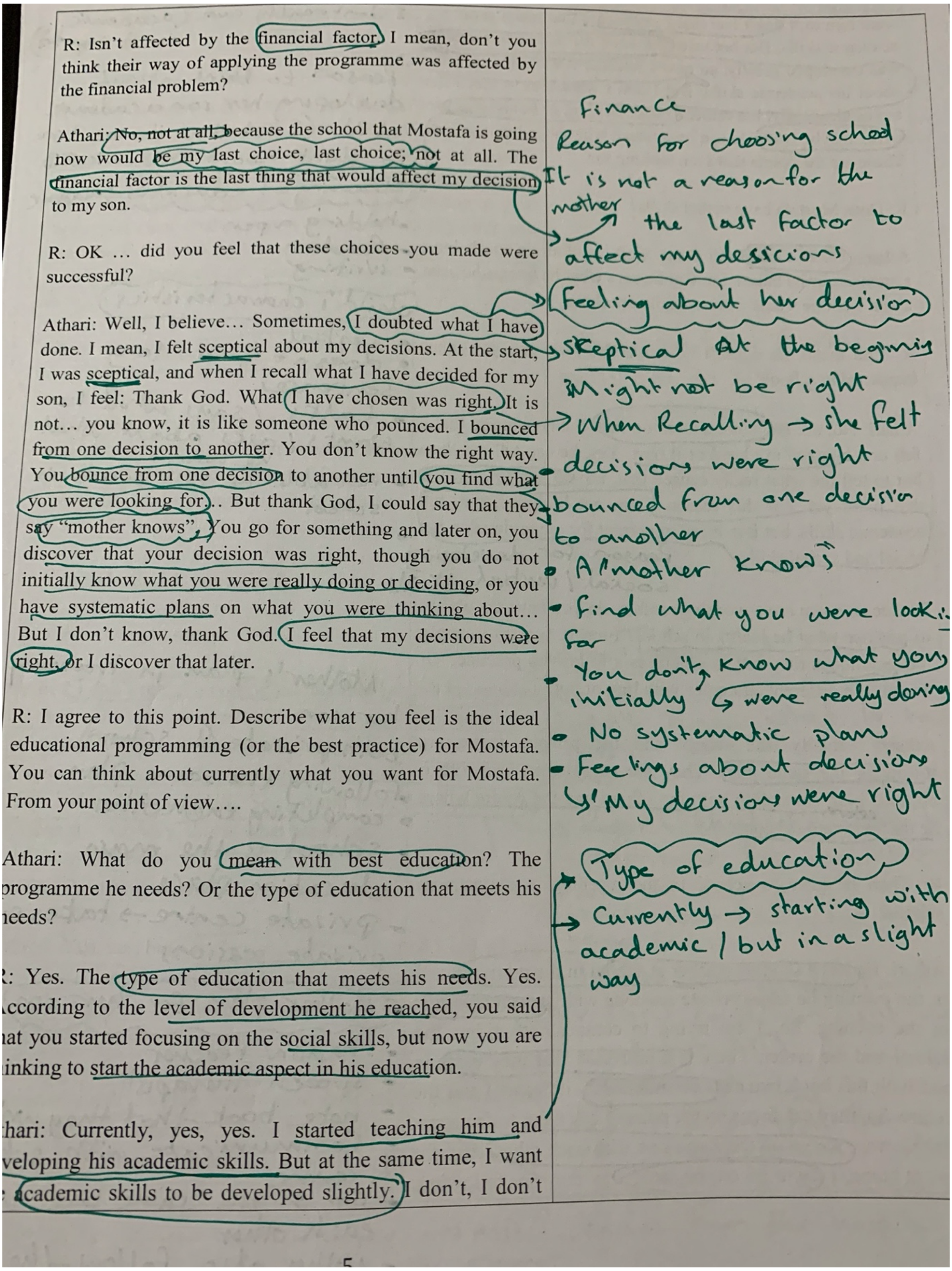
Mother can anticipate whether the school was able to work with her son or not from the way they describe the meaning of integration

Mother strategy
- spending days with school
- Asking them that her son would spend a day as wel
- Observe their way of dealing with him
- can decide if they are able to deal with him or not

Mother's opinion about the school's understanding of integration

Contradiction between understanding / talk and application

mother sense the school understanding wasn't wright



R: Isn't affected by the financial factor, I mean, don't you think their way of applying the programme was affected by the financial problem?

Athari: No, not at all, because the school that Mostafa is going now would be my last choice, last choice; not at all. The financial factor is the last thing that would affect my decision to my son.

R: OK … did you feel that these choices you made were successful?

Athari: Well, I believe… Sometimes, I doubted what I have done. I mean, I felt sceptical about my decisions. At the start, I was sceptical, and when I recall what I have decided for my son, I feel: Thank God. What I have chosen was right. It is not… you know, it is like someone who pounced. I bounced from one decision to another. You don't know the right way. You bounce from one decision to another until you find what you were looking for… But thank God, I could say that they say "mother knows". You go for something and later on, you discover that your decision was right, though you do not initially know what you were really doing or deciding, or you have systematic plans on what you were thinking about… But I don't know, thank God. I feel that my decisions were right, or I discover that later.

R: I agree to this point. Describe what you feel is the ideal educational programming (or the best practice) for Mostafa. You can think about currently what you want for Mostafa. From your point of view….

Athari: What do you mean with best education? The programme he needs? Or the type of education that meets his needs?

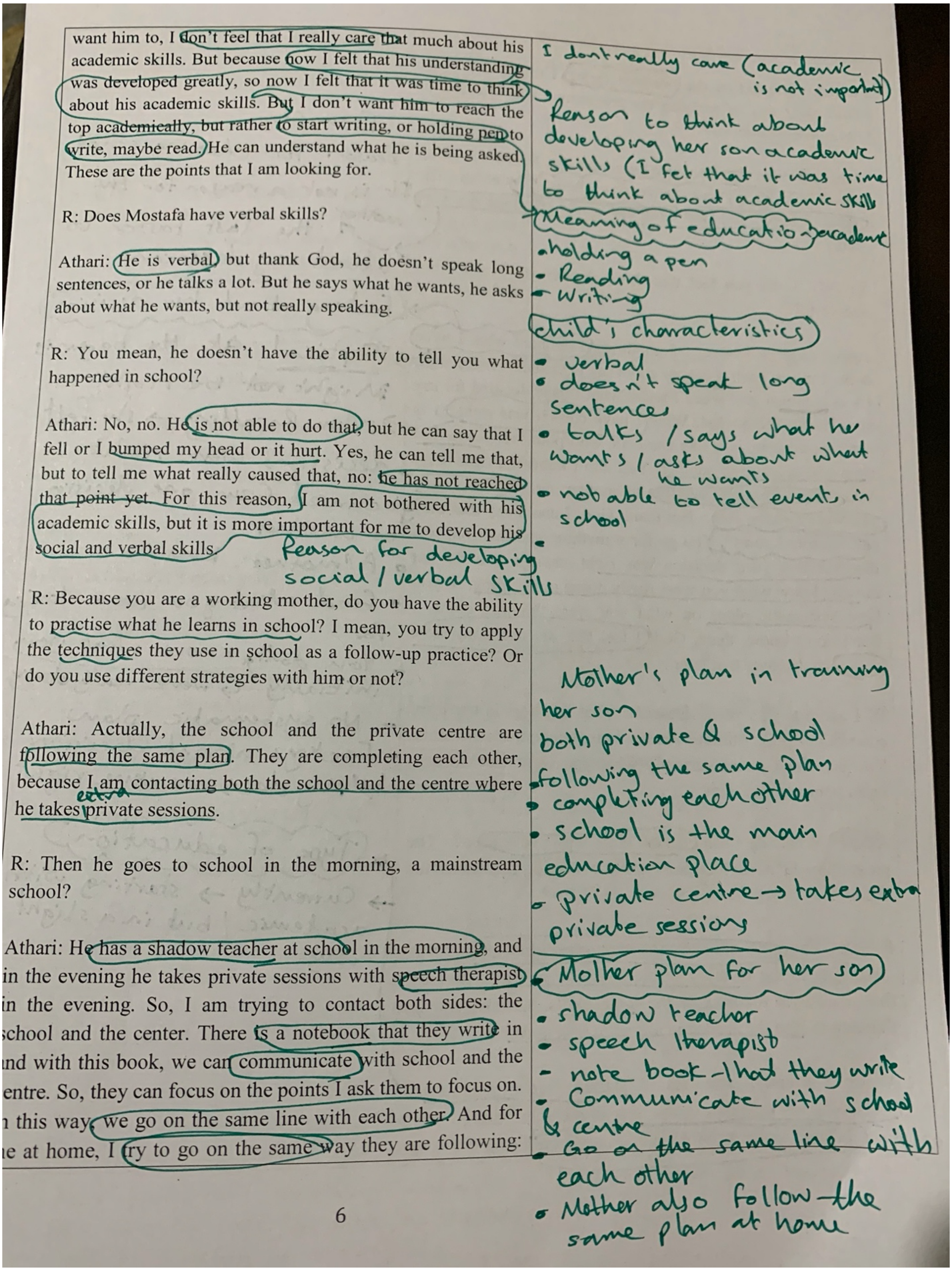
: Yes. The type of education that meets his needs. Yes. ccording to the level of development he reached, you said at you started focusing on the social skills, but now you are inking to start the academic aspect in his education.

hari: Currently, yes, yes. I started teaching him and veloping his academic skills. But at the same time, I want academic skills to be developed slightly. I don't, I don't

Finance
Reason for choosing school
It is not a reason for the mother
the last factor to affect my desicions

Feeling about her decision
- Skeptical At the beginnig
- Might not be right
- When Recalling → she felt decisions were right
- bounced from one decision to another
- A'mother knows'
- find what you were looki for
- You don't know what you initially were really doing
- No systematic plans
- Feelings about decisions 'My decisions were right'

Type of education
→ Currently → starting with academic / but in a slight way



want him to, I don't feel that I really care that much about his academic skills. But because now I felt that his understanding was developed greatly, so now I felt that it was time to think about his academic skills. But I don't want him to reach the top academically, but rather to start writing, or holding pen to write, maybe read. He can understand what he is being asked. These are the points that I am looking for.

R: Does Mostafa have verbal skills?

Athari: He is verbal but thank God, he doesn't speak long sentences, or he talks a lot. But he says what he wants, he asks about what he wants, but not really speaking.

R: You mean, he doesn't have the ability to tell you what happened in school?

Athari: No, no. He is not able to do that, but he can say that I fell or I bumped my head or it hurt. Yes, he can tell me that, but to tell me what really caused that, no: he has not reached that point yet. For this reason, I am not bothered with his academic skills, but it is more important for me to develop his social and verbal skills.

Reason for developing social / verbal skills

R: Because you are a working mother, do you have the ability to practise what he learns in school? I mean, you try to apply the techniques they use in school as a follow-up practice? Or do you use different strategies with him or not?

Athari: Actually, the school and the private centre are following the same plan. They are completing each other, because I am contacting both the school and the centre where he takes extra private sessions.

R: Then he goes to school in the morning, a mainstream school?

Athari: He has a shadow teacher at school in the morning, and in the evening he takes private sessions with speech therapist in the evening. So, I am trying to contact both sides: the school and the center. There is a notebook that they write in nd with this book, we can communicate with school and the entre. So, they can focus on the points I ask them to focus on. n this way, we go on the same line with each other. And for e at home, I try to go on the same way they are following:

I dont really care (academic is not important)

Reason to think about developing her son academic skills (I felt that it was time to think about academic skills

Meaning of education → academic
- holding a pen
- Reading
- Writing

child's characteristics
- verbal
- doesn't speak long sentences
- talks / says what he wants / asks about what he wants
- not able to tell events in school
-

Mother's plan in training her son
both private & school
- following the same plan
- completing each other
- school is the main education place
- private centre → takes extra private sessions

Mother plan for her son
- shadow teacher
- speech therapist
- note book - that they write
- Communicate with school & centre
- Go on the same line with each other
- Mother also follow the same plan at home

6

Appendix five: An example of quotes from participants' interview (Athari)

pg	Codes	Category	
1	-He understands that he is going to school for learning -I feel that he has not reached that level of understanding -Knows that he is going to school - He says he learned something at school, but the meaning of education/ learning I don’t think he understands it.	doesn’t understand school, Meaning of education, meaning of learning	Child’s characteristics
2	- I started to think about academic this year, because I noticed that Mostafa’s concentration and understanding are becoming better - I was not thinking about them in Mostafa’s development process. - But now I felt that he started to be sociable, he understands the meaning of school, he sits in the classroom, he is committed to school routine, he plays with other kids and so on. - I felt that it was time to think about academic skills and focus on them. But before, I did not think about it at all.	Child’s readiness for to academic skills	
5	He is verbal He doesn’t speak long sentences, or he talks a lot. He says what he wants, he asks about what he wants, but not really speaking. He is not able to do that, but he can say that I fell or I pumped my head or it hurt. He can tell me that, but to tell me what really caused that, no he has not reached that point yet.	Child’s characteristic	
5	I felt that his understanding was developed greatly, so not I felt that it was time to think about his academic skills	The starting point for academic skills	
2	I currently think about integrating him into the society. I am not focusing on his academic skills integration, developing concentration, developing understanding	Purpose of education	Meaning and purpose of education for her son
2	- I was not focusing on reading, writing.	Purpose of education	
2	-They might mean each other. In some cases they say learning and habilitation.	Mother’s definitions for education	

	-Habilitation might mean they start with it at the beginning of children's life and then they move to education. So education comes after habilitation. -Maybe can be in-depth learning, maybe.		
2	Therapy means cure, and medicine. There must be medicine in it	Mother's definition of therapy	
3	I don't think about education in a similar way that I think about it for his brother.	Differences in the meaning of education	
3	It depends on his achievement and the level he reaches	Meaning of education	
3	based on my experience, it is not important to get high marks, or go to college, or to get a degree	Mother's perception about education	
3	The most important is to understand, to comprehend everything around him	Meaning of education	
5	Start writing, or holding pen to write, maybe read I am not bothered with his academic skills	purpose of education (academic skills, writing and reading)	
5	It is more important for me to develop his social and verbal skills.	Mother's main focus on her child's development	
3	I visited school, I ask them about the programmes they have for children like Mostafa	Mother's strategy to choose a school	Mother's strategy to choose educational placement
3	They might say, 'no we cannot accept him in our school, or they cannot accept him in a mainstream classroom.	Schools rejections to her child	
3	I might ask them how do special classes operate and what do they do? I mean what are their programmes for children like Mostafa. What are you going to teach him? How are you going to integrate him? I ask all of these questions,	questioning them, talking to school teachers, listening to them about the meaning of integration	
3	After that I don't know, I feel that I know from my experience with many schools I can understand if they are going to integrate him or not from their way of talking about integration. Because their way of talking about integration reflected clearly through their talk. I can understand if they belief that these children can be integrated or not	Mother's decision based on her experience	

4	I also spent full days with the school from the start of the school day till the end, in order to see their performance I can see, I can observe their way of dealing with him,	Mother's strategy to choose a school spending full days in the school, observing	
4	Mostafa spent a full day with them. In this way I can see, I can observe their way of dealing with him	Mother's strategy to choose a school	
4	There were many schools, which didn't understand the meaning of integration. They will tell you that they were going to do many things, but when they speak about it and how they were going to apply the programmes. You don't feel it was right what they were doing.	Mother's perception about the school	
4	The financial factor is the last thing that would affect my decision to my son.	Factors of choosing the school	
4	Sometimes I doubted what I have done. I felt skeptical about my decisions, at the start . I was skeptical, when I recall what I have decided for my son. Thank God , what I have chosen was right. I bounced from one choice to another, mother's instinct "mother knows" You don't know the right way, you pounce from one decision to another until you find what you were looking for (Athari, I:4)	Mother's feelings about decision	Mother's feelings
5	I started teaching him and developing his academic skills. not important(Athari, I:4)	Mother's feeling about the academic skills	
6	I was so much satisfied in UK I don't regret anything I was not sure about his condition I have never regret anything after he had his diagnosis when we came back from UK satisfied, no regret	Mother's feeling about her decision	
6	I regret his early stage before I went to UK. So I could have done something differently.	Mother's feeling about diagnosis	
6	I understood his condition differently and I was taking a different path than ASD. I only felt that his condition was related to his speech. Yes I started sessions for him, but I never knew that there were special schools so I could talk to them. I just depended totally on the government hospital, which was one session per week.	Mother's feeling about diagnosis	

	If I have known this as what I know now, I would have doubled the sessions he had. Instead of focusing more on my study, I would have dedicated more time for him. (Athari, I:6)		
7	I was not really sure about what he should learn or what programmes were suitable for him. I was not sure what Mostafa's needs. (Athari, I:7)	Mother's feelings about her decision	
7	For example, his teachers wants to start with some points, which I felt were not important at that stage for him. So I tell them to adapt these points to suit Mostafa's needs. My way in doing this caused me some troubles with the teachers. I know that they are not the best teachers ever that my son could have but at least they are better than others. I need to follow them up and ask them to train him on what he needs. Sometimes they ignore certain points that Mostafa needs to be developed in I know Mostafa more than them. I know his needs because I live with him and I spend more time with him	Mother's feeling about his teacher	
7	I tried to change myself to be more patient and being more accepting for his condition(Athari, I:7)	Mother's feeling towards her son's condition	
9	I feel that I am still not able to make decision for him. I do not feel that I have the ability to make decisions. Everyday, I discover new things about ASD, and about my son. The situation is more obvious for me than before.	Mother's feeling about her decision	
9	I have hope that my son one day he will be a "normal" child like many other children. But I adopted myself to live with autism.	Mother's feelings for her son's condition	
9	Sometimes I have depression moments. You know that I feel ok most of my time, but there are days that I go through depression moments. Later on I get out of these moments.	Mother's feelings for her son's condition	
9	I am a person who could try to find different ways to get out of my depression.		
16	I have mixed feelings. There are times that I feel happy because I have achieved something.	Mother's feeling about her son's condition	

	I became more appreciative for the development of my both children. I sometimes feel worried about, but it is not intense. I also don't feel sad, I developed strategies to get me out of my sadness. I also developed trust in everything around me. I sometimes feel guilty, like if I was aware of his condition I would not have left him using electronic devices. I always feel success when I see my son's development. (Athari, I:16)		
12, 13	I feel I can manage my stress I am capable to face challenges but I don't know about the future, because Mostafa is still young and I am not sure about him How I am going to face the challenges that might come up. I really don't know. At this age, yes I can do it and I encourage myself not to think about the future. (Athari, I:12)	Mother's feelings about facing challenges	
13	I don't know if you look at it as a balanced life or not, because everyday, is really hectic day, from early morning to evening and I am running form one place to another. Honestly this is adding pressure on me. I always feel that I am under pressure. There are many times that I feel that I need to reduce some of the activities for Mostafa, even the evening sessions. I know that Mostafa is benefiting from these sessions, but also I am adding pressure on me. I am really exhausted, and I don't feel that I really have a social life like before. I feel that I have stopped contacting many people, even my colleagues at the work. I don't know but I really feel that I am a way from many of them. I am here and I am feeling exhausted. I have reached to a point that I don't know what I am doing. At the work they ask me to present paper in a conference, and I don't know what I want to present. I mean I always ask myself what I want to do, either I focus on my job and dedicate my effort and time towards my job so, I get promoted. This will cause me reduce my efforts	Mother's feeling about her life with a child with autism	

	towards Mostafa and I have to give up many things related to my son’s development, which I don’t want. This is what I feel currently, I really don’t know what I want. I don’t know. (Athari, I:13)		
5	the school and the private centre are following the same plan. They are completing each other, because I am contacting both the school and the centre where he takes private sessions	Mother’s strategy for her child’s development	
5	I am trying to contact both sides the school and the center. There is a notebook that they write in and with this book we can communicate with school and the centre. continuous contact with the teachers in the school, private centre using notebook	Mother’s involvement in her son’s education	
5	I try to go on the same way they are following (the school and the centre). I try to generalize the things they give him in the centre and the school so it can be applicable for our life at home. (Athari, I:5)	Mother’s strategy at home (practice what is given at school, modify some tasks)	
7	I was reading a lot, I became better in understanding the programmes. I also became better to understand Mostafa’s conditions. I became better in comparing his needs to others.	Mother’s understanding for her son’s condition	
7	I was trying many things,So I tell them to adapt these points to suit Mostafa’s needs I was not asking them to do lot of work with my son, because I felt that he was not prepared yet for the skills they wanted to work on. I wanted them to work in an appropriate way with Mostafa. Even at the centre, sometimes there were teachers who wanted to jump form one skill to another when I felt that he was not ready yet for what they wanted to do. Generally they accept my recommendation to Mostafa’s programme. (Athari, I:7)	Mother’s involvement in her son’s education	
7	love and cuddle is more effective than being strict with him. Being strict with Mostafa doesn’t work at all. I tried to change myself to be more patient and being more accepting for his condition , my son became better (Athari, I:7)	Mother’s strategy with her son at home	
7	I stopped his use to these electronic devices	Mother’s strategy with her son at home	

	He started to develop comprehensive behavior in a better way. I give him these devices in a manageable way. Electronic devices are really bad for his concentration and comprehension.I stopped his use for the phone. (Athari, I:7)		
8	I give it to Mostafa as a kind of reinforcement for a good behavior. I give him the phone to use a certain application that might help him or play a game and I time the use. I started to follow a certain programme, I took the parts that were convenient to me. These helped him a lot and he became better in comprehending the world around him. I allow him to watch TV and he likes to watch funny series, because these make him happy (Athari, I:8)	Mother's strategy in developing her son's skills	
8	I use it as reinforcement, because he understands it and he uses the phone for short time. He did not realize that he needed to use the phone for a short time and he had to give it back. He was using it for a long time and if we take it away, he would have tantrum and caused his development to slow down. (Athari, I:8)	Mother's strategy for her child's development	
11	He is abide by the house rules	Mother's strategy at home	
11	His father arrives home, so he takes his turn to take care of him, so he takes him to his room, he reads stories for him or they play with each other until they sleep both of them.	Mother's strategy at home	
11	Sometimes in weekend we look through his homework, because I asked them in the school not to give him any homework except weekend.	Mother's strategy at home	
11	The driver takes them, because I never wanted him to go with the school bus. I also do not trust the driver to bring him home alone, so the housemaid goes with him and brings him home.	Mother's strategy to help her son	
8	I noticed that Mostafa was clever boy.	Mother's perception about her child	Mother's perception about her son's development
11	Mostafa is an organized boy This doesn't mean that he is a routine person because of autism symptoms	Mother's perception about her son	

13	He has developed greatly	Mother's perception about her son's development	
7 12	Mostafa used to use the electronic devices in a very negative way. I can say he was addicted to them. I say that this addiction was my biggest fault I feel that Mostafa's main reason that made his condition worse was his use of electronic devices.	Mother's perception for the cause of her son's condition	Causes of her son's condition
8	He was a way from the real world. When he uses the phone, he forgets everyone around him. He never responded to anyone's calls. The phone was taking his mind away. He was using it for a long time and if we take it away, he would have tantrum and caused his development to slow down.	Effect of Overuse of electronic devices	
6	The school's system to have a shadow teacher for children with special needs.		Mother's perception about public services for children with ASD
7	I know that they are not the best teachers ever that my son could have but at least they are better than others.	Mother's perceptions about her child's teacher	
8	In contrast, in the centre they did not agree with me in this point. I mean, they always encouraged me to give the phone to use it.	Conflict between mother and centre with regards the use of electronic devices	
12	I don't feel that they are well-prepared for understanding children with autism. I am afraid that they will not take care of him.	Mother's perception about public mainstreams	
12	The school is really big and the teachers are overloaded, and not prepared for children with autism. The situation depends on each child, the school size, the cooperation of teachers, the region the school is in. But in the capital city, I don't really advice parents to send their children to a main public school, except if their parents have low house-hold income.	Reason for not trusting these schools	
12	In some regions the number of the students are not big, and there are not many private schools, in that case parents might not be able to send their child to. In	Mother's perception about public	

	that case they can not leave them at home, so it is better for them to find a place even if it is not the best.	mainstream schools	
13, 14	I cannot see many services offered by the ministry of social development except the habilitation services. They offer habilitation sessions to children with ASD. I mean they pay for these sessions even if it is in a private centre Children will not develop because the sessions are not enough for both of them They issue a card for children with autism I have never seen any support from them, even we asked them several times to add services on the card for children with disability, but it is just a card.	Mother's perception about services for children with autism	
14	They have some services but they are not enough	Mother's perceptions about Ministry of Social Development	
14	Ministry of Education, is not even doing anything as if these children are not it is not the Ministry's responsibility.	Mother's perceptions about Ministry of Education	
14	There is no support and the people who are working in these Ministries do not understand their job. They think it is just a job for the sake of salaries and once their working hours is over, that's it. Because their responsibilities require social and emotional involvement to consider and provide parents with their needs, few employees who are sincere in their job.	Mother's opinion about the two ministries	
15	They had unrealistic evaluation process. The specialist are not qualified. At the end they stopped the project because of financial reasons.	Mother's perception about the Ministry of Education's work for the children with autism	
12	I adviced her to read more about autism and directed her to different autism websites. I also advised her to stop giving him electronic devices, because you know that I am affected with them. I also advice them to start as early as possible and they take them to centres that have specialist who are really good.	Mother's advice to a newly diagnosed with autism	

	If you are able to work with your son/ daughter, if not at least you can support his development at home. look for a nursery that accepts him with his condition.		
12	They must have some involvement in their education. They must contact the teachers in a regular basis, so they know what your child needs.	Mother's advice to all mother's of children with autism	
13	There are many mothers who are worried about their children's future, but I really don't think that this is healthy, I feel that we need to live each stage without thinking about future or even past.	Mother's advice to all mother's of children with autism	
9	Whenever, I feel I was ready for a new plan, I discover that there were new things in Mostafa, I have never noticed before. New things or symptoms appeared in him I have never thought of.	Reason for uncertainty about her decision	
9	The more I read and the more I talk to specialist, I discover new things, I was not aware of. I listen to mothers talking about their children, I discover things I have never thought of.	Mother's source of information	
10	I always try to benefit from everything around me. I think deeply when they talk about different things around me or when mothers discuss different topics about my autism. I try to analyze the topic being discussed and relate them to my son. This helped me to develop a better understanding about autism.	Mother's ways to understand autism	Mother's ways to understand autism
9	Everything and everyone my job is really flexible and considerate to my son's situation. My husband is really very supportive though his job is really difficult. My husband is really supportive. He supports all the plans I set for Mostafa's education. He supports me in every step.	Factors helped her to deal with her son's development	Family support
10	There have been many people who helped me and supported my son's education. Even the mothers in the whatsapp group. Mostafa's brother is becoming better in understanding his brother's condition. Even my family, my sisters are all helping me.		

	I recruited all my sisters and my nieces and nephews to support me with Mostafa. The housemaid is also helping me with my son. She is really different and supportive.		
5	He is in a mainstream school in the morning and private centre in the evening	The child's current education	
5	He has a shadow teacher at school in the morning, He takes private sessions with speech therapist in the evening. There is a notebook that they write in and with this book we can communicate with school and the centre	School's strategy with a child with ASD	
8	I really don't know, I have never thought about it. At the beginning it might be difficult for him,	The effect of transfer from one school to another on child	Transition from school
8	The beginning was difficult for him because it was a new school and a new environment. The teachers were also new for him. But later on they were able to manage him and work with him.	Transition is difficult	
10	setting plans, following up, involving family members in her son's development	Mother is the main person in the child's education	
11	routine, planed, abide to house rules,	Child's typical day	
15	I wish that he depends on himself. I don't think about Mostafa to be a doctor or an engineer. My biggest dream is just to depend on himself. To be a doctor, is not important to be me.	Mother's hopes for her child	
16	I am leaving this to God. I can not change the future . I have some fears, but I try to think about my day and not more than that.	Mother's fears about her son's future,	

Appendix six: Story narration summaries

Mothers Narration

Anfal

Anfal has a child with ASD, Khamis. She started training her son at the age of 4 and she said that she never heard the word “autism” before diagnosing her son. She informed herself through looking and searching for information about autism in books and in the Internet. Anfal’s family is supportive and cooperative in taking care of her son with autism. She tries to develop her son’s skills at home through using games and stories. Though Khamis is independent in most of life skills such as going to the toilet or eating and he is able to read and write, Anfal struggled to find a place for him in government mainstream schools, a mainstream class. He was in a government special school, but they moved him recently to a government mainstream school in a special class for children with SEN.

Aseel

Aseel described her son’s, Marwan, level of autism as severe. He is at the primary level age and he is in a government special school for children with SEN. She tried to use prescribed recipes and food supplement to increase her son’s concentration span and reduce his hyperactivity. She registered Marwan in a private special school, but she noticed that Marwan acquired negative behivour such as biting and flapping. So she moved him to another special school funded by the government. At home she uses games and focused activities to develop Marwan’s skills. Aseel is a working mother, but her family is very supportive. Her sisters and sisters-in-law help her in taking care of Marwan when she is at work.

Athari

Athari is a working mother and her son with autism, Mostafa, is a primary age child. She had many delays in her search for answer about her son's behavior. Though she travelled to UK for her studies and there he was diagnosed with autism, she did not understand that autism was a serious condition that she needed to worry about. According to her, in UK, specialist comforted her that her son would be fine as he grew up. But her real struggle started when she went back to Oman and could not find a place that satisfied her. This made her stressed, depressed and she isolated herself from the community. She went to many private and government schools and she faced rejection from most of them. Later, she found an acceptable school that would help developing her son's social skills. Mostafa is now in a private mainstream school with the support of a shadow teacher (teacher assistant) who support Mostafa's social and academic skills. In addition Mostafa is taking evening session to work on social and life skills.

Fadwa

Fadwa described her son Affan as her "little hero", who taught her to think about life and knowledge differently. Affan is a middle school boy. Fadwa is a working mother and she realized that her son needed support more than she expected. When Affan was diagnosed with autism, she had a mixture of fear and sadness, which she could not describe. She tried many programmes to develop her son's skills. In addition, she developed her skills to train her son through, attending workshops, conferences and seminars about autism. Affan is now in a private special school and Fadwa found support from her family and friends to develop Affan's social skills.

Fatin

Fatin is a mother of two boys with autism, Khozam and Hassan, she described the eldest son’s level of autism as severe and Hassan, the youngest as a mild level of autism. Khozan has autism and a mild brain disability. She travelled to different countries to understand her son’s condition and to find a therapy. Fatin tried to develop her son’s condition through using medication, speech therapy and vocational training. Khozam is now integrated partially in an international school in a nearby country with a mentor who accompanies him. Her second son, Hassan is in a private mainstream school in Oman. Fatin supported Hassan by mixing him with typically growing children. Fatin started early intervention for her son in order to develop his social and academic skills. In addition, she tried to develop her skills in dealing with her son and she finished a diploma degree in teaching children with SEN.

Ibtihal

Ibtihal is a mother of Yahya, an 8-year-old boy diagnosed with autism. She questioned his condition at the age of 16 months as he changed dramatically and developed weird behaviours such as hyperactivity, problems in speech and repetitive actions and hysterical laughter or constant crying with no reason. She suffered from depression, which made her to start taking medication. But then she realized that her son needed her, she started to develop her knowledge about autism through searching Internet and reading books. She used many strategies to develop her son’s social, life and academic skills. Her son was rejected from many schools; with a struggle she managed to find a place for him in a government mainstream school with typically growing children. She faced accusation from her family with negligence and carelessness towards her son and she did not have support and help from her family.

Jori

Jori's son, Mishari, is a child with autism at the age of nursery level. She described her son's level of autism as moderate. She travelled abroad to find the answers for her son's delay and behavior. She was shocked that her son needed an intensive training and habilitation in order to support his speech skills. She thinks that she is at the beginning of her journey with autism. She explained that mothers of children with autism in the whatsapp group are inspiring her with penitence and hard efforts. She trains her son at home as well as he goes to a private special school.

Jumana

Arif, Jumana's son, is in a private mainstream school. She described her son's level of autism as mild. She managed to develop Arif's social, life and academic skills through mixing him with other children. He is now in a private mainstream school studying with other typically growing children. Jumana developed her knowledge about autism through searching the Internet and social media.

Maha

Maha, thinks her son (Jamal) is a clever 9 years old boy. He did not find the support from many governmental institutions. Though Maha did not have any idea about autism, she was shocked that he son had been diagnosed with autism. She decided to use different strategies to "treat" and "educate" her son such as using medication, diet therapy and functional therapy. Maha and her son encountered rejection from schools which were not many, because they live in an area outside Muscat. However, they found a place for him in a governmental special school which, she thinks, supported Jamal's development. Maha's family is very supportive and considerate. Maha played a significant role in Jamal's progress, through increasing her knowledge about autism and the ways to support a child with autism.

Maria

Maria is a mother of Adnan a primary school boy. She is a working mother who thinks that leaving hear son in front of TV caused his autism. After diagnosing her child with autism, she refused to accept this for years. Until she joined a group of mothers of children with autism, she started to accept autism in her life. She started to develop strategies to develop her son's social and academic skills. Adnan is in a private special school for children with autism. Maria thinks that he has developed greatly and learned reading and writing.

Mayada

Al-Wraith is Mayada's son who was diagnosid with autism could not find the answer for her question in Oman and preferred to take him to an Asian country more than once. She was looking for a "cure" for her son's condition. Al-Warith was rejected from many places in her town and she could not move to Muscat and could not provide him with an intensive training because of financial reasons. Though Mayada managed to enroll her son in a government special school, she feels this is not helping her son.

Narjis

Amjed is Narjes's son, a primary age boy. She hoped that her son's condition was caused by his hearing problem, but her hope faded when she noticed that Amjed's main problem was not related to hearing. She was forced to move from her town to Muscat as she thought there were not many places for her son. She had applied many strategies to help the development of Amjed's social, communication and life skills. She agreed with speech specialist to come to home to support his speech development and she used diet and medication as a therapy for her son. Narjes has changed the schools that Amjed goes to several times, because she thinks that these special schools are poorly equipped and they did not meet her son’s needs.

Nirmin

Nirmin is a mother of Al-Molham who was diagnosed with autism, like many of the previous mothers, she was shocked and disappointed when she knew about her son’s condition. As a way to support her son, Nirmin joined her son in the school, so she could develop his social skills by mixing him with other children regardless her disappointments towards his running, flapping or screaming. Then she succeeded to enroll him in a privale special school. She thinks that the school assisted Al-Molam’s progress as well as her insistence to support his speech. She thinks that the community has been unfair with her son and her family have never accepted him. This caused her to close her door and lock herself at home. She always felt tired, sad and isolated.

Njood

Salman is a middle-aged school boy diagnosed with autism. Njood had many delays in her son’s condition and was told that he was fine. She did not have a precise diagnosis, but she felt that there was something in her son that she did not understand. She enrolled Salman in a school for special needs at the age of 7. This made it very difficult for him to respond to the training and his development was very slow. Salman was rejected from private schools, but she managed to find evening session for him and she hired a private teacher in the morning at home. Njood thinks that no one can endure a child with autism, but they generally seemed to understand Salman’s behavior.

Rafif

Rafif started with her son without a diagnosis, but many characteristics of autism had been described to her. Autism was vividly understood through her intensive search about her son’s condtion. She was sad, depressed and she suffered from denial of what her son had. She did not send her son to any school and she trained him at home. She tried different ways from the internet, she worked hard, adapted and changed startegies to meet her son's needs. Despite much frustration around her, she had strong faith that encouraged her to continue. Rafif's family was supportive, but there were some people who never understood what a family of a child withautism went through.

Rahaf

Rahaf's son, Mansoor, is the fourth among his sibling. She was told that she needed to "wait and see". She questioned his behavior and after many appointments with specialists, she managed to get a diagnosis. No words could describe her feelings about this, but she had the confidence that she would help her son. She managed to change her family's way dealing with her son to be positive. She enrolled Mansoor in a private special school to develop his visual and social skills and to overcome his sleep problems. Mansour is still young, but Rahaf always has concerns about his future.

Razan

Razan is a mother of a teenager girl, Khamail, who has the diagnosis of autism since she was two years old. She seems to think that her daughter was affected with an evil eye that changed her daughter from a typically growing daughter to a girl with strange behaviours. She was confused and shocked because she had been told that Khamail had a brain deficit. Through Razan's intensive search by reading books and meeting specialist about her daughter's behavior, she started to understand autism. She enrolled Khamail in private special school and cooperated with the specialist in the school to develop her daughter's skills. Besides Razan's continuous reading about autism, she joined a course and took a diploma in special needs in which she would help her daughter.

Samaher

Samaher is a mother of two children with autism Sami is 14 years old and Samia is 8 years old. She seemed not to have a clear diagnosis about her son, but she could enroll her son in a government mainstream school and he is now in year 5. He missed two years of school, but he is doing well now. Samia was diagnosed with autism and Samaher managed to enroll her in a government special school, but she felt that her condition was getting worse, so she decided to off-roll her from school. She teaches her daughter at home through using photos.

Shahad

Shahad is like Njood, had many delays in her son's diagnosis. Though it was clear for her that Mojahid was unlike his siblings in the development of main skills. Shahad had to travel out the country to find the answers for her son's condition. There, Mojahid was diagnosed with autism. Shahad and her family had to move from their town to another one where there was a special school for her son. After two years, they had to go back and find another school. Shahad thinks that taking care of a child with autism is a real burden on the family.

Shojoon

Shojoon is a working mother who has two daughters with autism. Hoor is 8years old and Noor is 4.5 years old. She decided to talk in this research about Hoor the eldest daughter. She was not convinced with the diagnosis done for Hoor in Oman, so she travelled to an Asian country to find out the answers for her daughters behavior. When she was told that her daughter had autism, she started to set a plan to support her development. She enrolled her in different private and government places and brought specialist to home to support Hoor. Many reasons forced Shojoon to change her plans for her daughter from time to time. She thinks that mainstream schools are not qualified to receive children with autism.

Somood

Somood is a mother of Tariq, a primary age boy. She initially was skeptical that her son had hearing problem. Then she knew that he had autism when he was 4 years old. She tried to “treat” him in private centres, but she stopped because of the expensive costs of these treatments. Though Somood’s family is very supportive, she suffered from grief, despair and sorrow because she thinks that she cannot help her son. She always pray to God to ‘cure’ his ‘illness’.

Sondos

Sondos is a mother of Munthir, a six years old boy, was diagnosed with autism. She was told that her son was fine though she had doubts about his hearing. After her son’s diagnosis with autism, she started questioning his condition and ended up that autism is a “dark world”. Like many mothers in this research, she tried many things such as nutritional supplement (diet therapy) and medication. She thinks that there is a lack of services in the country as well as there is a lack of awareness in the community about autism.

Thana

Thana’s son Majed is 18 years old boy. She thinks that Majid’s condition was caused by an evil spirit, when he was 10 days old or he inherited epilepsy from his father. He was rejected from many government schools and there were not many special schools for children with autism. Therefore she sent him to a specials school in one of the Arabian countries. He stayed there for three years, but she decided to bring him back, because of the ill treatment he had there. Now he is at home and his mother is home-training him. Thana hopes that one day she will hear Majed’s voice calling her.

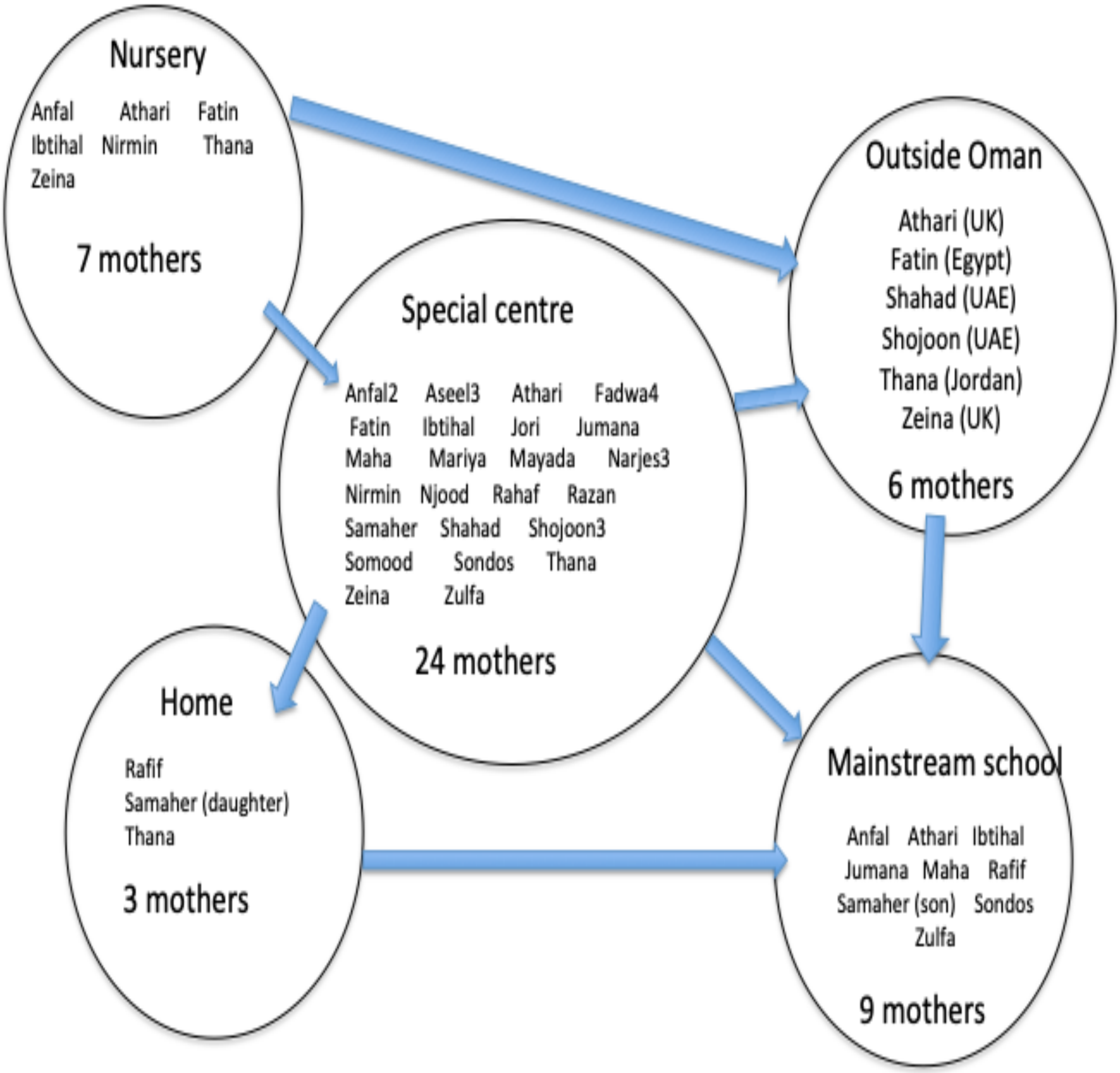
Zeina

Zeina’s son Obaid is 8 years old boy who is studying in a special school in UK. She thinks that she is luckier than many other women, because the diagnosis and care was done in UK. According to her “not many children have received the services that Obaid have”. Zeina noticed that Obaid was not growing typically like many children in his age and she immediately attempted to find a diagnosis. At that time she was studying in UK and she did not feel that autism was something to worry about, because her son had a plan. However, a devastating incident happened to her changed all her plans and she had to go back to Oman and set up a new plan for her son. Few years later, she managed to come back to UK for her PhD studies and Obaid is now in a special schools in UK.

Zulfa

Zulfa is a mother of a primary age boy diagnosed with autism. She managed to support her son’s development through diet therapy, speech therapy, vocational therapy and home intensive care. With a struggle she was able to enroll him in a private mainstream school. Now she thinks that she succeeded in developing her son’s skills to be a typically growing boy.

Appendix seven: Example of analysis



Appendix eight: Ethical approval

COLLEGE OF SOCIAL SCIENCES AND INTERNATIONAL STUDIES

When completing this form please remember that the purpose of the document is to clearly explain the ethical considerations of the research being undertaken. As a generic form it has been constructed to cover a wide-range of different projects so some sections may not seem relevant to you. Please include the information which addresses any ethical considerations for your particular project which will be needed by the SSIS Ethics Committee to approve your proposal.

Guidance on all aspects of the SSIS Ethics application process can be found on the SSIS intranet:
Staff:
https://intranet.exeter.ac.uk/socialsciences/staff/research/researchenvironmentandpolicies/ethics/
Students:http://intranet.exeter.ac.uk/socialsciences/student/postgraduateresearch/ethicsapprovalforyourresearch/

All staff and students within SSIS should use this form to apply for ethical approval and then send it to one of the following email addresses:

ssis-ethics@exeter.ac.uk This email should be used by staff and students in Egenis, the Institute for Arab and Islamic Studies, Law, Politics, the Strategy & Security Institute, and Sociology, Philosophy, Anthropology.

ssis-gseethics@exeter.ac.uk This email should be used by staff and students in the Graduate School of Education.

Applicant details	
Name	**Raya Al Raesi**
Department	**School of Education**
UoE email address	**Rsa205@exeter.ac.uk**

Duration for which permission is required		
You should request approval for the entire period of your research activity. The start date should be at least one month from the date that you submit this form. Students should use the anticipated date of completion of their course as the end date of their work. Please note that retrospective ethical approval will never be given.		
Start date:01/11/2017	**End date:01/07/2018**	**Date submitted:13/11/2017**

Students only	
All students must discuss their research intentions with their supervisor/tutor prior to submitting an application for ethical approval. The discussion may be face to face or via email. Prior to submitting your application in its final form to the SSIS Ethics Committee it should be approved by your first and second supervisor / dissertation supervisor/tutor. You should submit evidence of their approval with your application, e.g. a copy of their email approval.	
Student number	**650059586**

Programme of study	Select programme from dropdown list **PHD Education, Special Education Need**
Name of Supervisor(s)/tutors or Dissertation Tutor	**Hazel Lawson** **Alison Black**
Have you attended any ethics training that is available to students?	For example,: i) the Research Integrity Ethics and Governance workshop: http://as.exeter.ac.uk/rdp/postgraduateresearchers ii) Ethics training received on Masters courses If yes, please specify and give the date of the training: **Understanding Research Ethic,** 25/10/2016

Certification for all submissions

I hereby certify that I will abide by the details given in this application and that I undertake in my research to respect the dignity and privacy of those participating in this research. I confirm that if my research should change radically I will complete a further ethics proposal form.

Raya Al Raesi

Double click this box to confirm certification ☒

Submission of this ethics proposal form confirms your acceptance of the above.

TITLE OF YOUR PROJECT

Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).

ETHICAL REVIEW BY AN EXTERNAL COMMITTEE

No, my research is not funded by, or doesn't use data from, either the NHS or Ministry of Defence.

If you selected yes from the list above you should apply for ethics approval from the appropriate organisation (the NHS Health Research Authority or the Ministry of Defence Research Ethics Committee). You do not need to complete this form, but you must inform the Ethics Secretary of your project and your submission to an external committee.

MENTAL CAPACITY ACT 2005

No, my project does not involve participants aged 16 or over who are unable to give informed consent (e.g. people with learning disabilities).

If you selected yes from the list above you should apply for ethics approval from the NHS Health Research Authority. You do not need to complete this form, but you must inform the Ethics Secretary of your project and your submission to an external committee.

SYNOPSIS OF THE RESEARCH PROJECT

Maximum of 750 words.

The aim of this study is to develop an understanding about Omani mothers' experience, perceptions and feelings regarding educational choices and decisions for their children with

Autism Spectrum Disorder (ASD). The number of children identified as having ASD in Oman is increasing as it is worldwide and there is an accompanying need for an increase in educational services that can support their development. Children in Oman often encounter a lack of educational services and parents (particularly mothers) experience this differently. Mother can vary in their experience, perceptions and feelings, according to different aspects associated to child's diagnosis, different understandings of the meaning of education suitable for their child and many other aspects. These experiences, perceptions and feelings may lead parents to think differently about the choices and decisions they make when they choose the education for their child at different stages of the child's life and the strategies they use themselves. There have been few studies undertaken to investigate how parents choose the education of their children on the autism spectrum over time in Oman and neighbouring countries.

The research aims to answer the following main research question:

What are Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with ASD?

Specific research questions

1. What are mothers' experience, perceptions and feelings about the diagnosis of their children with ASD?
2. What is the meaning of 'education' for mothers in relation to their children with ASD?
3. What are mothers' experience, perceptions and feelings about the educational services provided by the government to their children with ASD?
4. What strategies are used by mothers in the education of their children with ASD over time?
5. What factors influence mothers' choices and decisions regarding educating their children with ASD?
6. What are mothers' experience, perceptions and feelings about the major challenges or barriers in educating children with ASD in Oman?

This study is concerned with understanding a relatively an un-researched area with the purpose of unearthing new insights (Robson & McCartan, 2016). The research questions aim to seek new insights that could open new avenues and research opportunities in the field of ASD in Oman. They are aimed at exploring mothers' experience, perceptions and feelings about the meaning of education for their children, and the impact of these on the educational choices and decisions. Through this study, I will strive to better understand how ASD diagnosis impacts upon mothers' experience and understanding of the education of their children with ASD. Furthermore, my objective is to gain a better understanding of how mothers choose the education for their children with the experience of their diagnosis, the symptoms, the characteristics associated with the condition that could affect their choice of the children's education as well as the meaning of education in reference to the children's needs. I aim to answer these research questions through accessing and listening to the mothers' stories about their children with ASD, the experience they have had, and the educational choices and the decisions made from the start of their diagnosis and through their educational stages.

This research will involve three phases:

The first phase will be self-constructed story narration: Participants will be asked to record or write their stories independently, without the researcher being present. The researcher will give prompts to them to consider in the telling of their stories.

The second phase will be semi-structured interviews: This will be used to gain a more in-depth understanding of mothers' experience, perceptions and feelings.

The last phase will be building-rapport days, in which the researcher will spend a day with a mother and her child and observe her strategies in relation to education as well as holding informal conversations with her.

INTERNATIONAL RESEARCH

The research will take place in Oman with mothers of children who have been diagnosed with ASD. There are no officially mandated procedures in Oman that are needed for this research. However, I will liaise with the Oman Autism Society in order to have access to participants and a detailed information outlining procedures and methods will be sent to this Society.

The second and third phase of the research interviews and the building-rapport days will take place in Oman.

The following sections require an assessment of possible ethical consideration in your research project. If particular sections do not seem relevant to your project please indicate this and clarify why.

RESEARCH METHODS

This research will consist of three phases in order to answer the research questions:

1. Self-constructed story narration: written or orally recorded stories narrated by mothers of children with ASD about their experience, perceptions and feelings with regard to educational choices and decisions for their children with ASD. For this phase there will be approximately 25 participants. The researcher will give prompts to them to consider in the telling of their stories.
2. Semi-structured interviews: Face to face interviews with mothers of children with ASD. These interviews will be in Arabic and will be carried out in Oman. There will be approximately 15 participants in this phase selected from phase 1 (see Participants section below). These interviews will be audio-recorded, dependent upon participant consent.
3. Building-rapport days: Spending a whole day with a mother and a child with ASD. There will be approximately 5 participants for this phase selected from phase 2 (see Participants section below). Field notes will be used to record these days.

It is likely that the self-constructed story narrations, semi-structured interviews and building-rapport days will be conducted in Arabic as the mothers may not speak English. It is possible that some mothers may be familiar with English, or for whom it is the preferred language. If this is the case they will be offered the opportunity to participate in the research in English.

PARTICIPANTS

The sample for all phases will be based on voluntary participation.

The recruitment of participants for phase 1 will be through 1) personal contacts, as I am part of a whatsapp group (a chat application) consisting of Omani mothers of children with ASD, 2) the Oman Autism Society, an official organization authorised by the Ministry of Social Development which deals with families of children with ASD, and 3) snowballing.

Participants in phase 1 will be asked if they would volunteer for an interview. If there are more than 15 volunteers, then the following criteria will be applied to obtain a participant sample for phase 2 with a mix of characteristics. This demographic-type information will be gathered alongside the narration in phase 1.

1. Ages and school stages of children with ASD age 4-18 (as this is the age of children who usually receive education in Oman.
2. Level of ASD diagnosis: severe, moderate, mild.
3. Type of education system (public, private, segregated or non-segregated, home-schooling).
4. Geographical location of families (from north to south, rural - urban)
5. Socio-economic status (from lower to upper classes).
6. Parental educational background (from uneducated to post graduate).
7. The number of children with ASD in the family.

Participants from phase 2 will similarly be asked to volunteer for phase 3, that is, to accept me spending an building-rapport day with them. If the number exceeds 5 volunteers, I will select according to three main criteria (drawn from the list above):

1. A range of ages and school stages of children with ASD age 4-18 (as this is the age of children who usually receive education in Oman. (Stages of schooling from early intervention to year 12).
2. Type of education system public, private, segregated or non-segregated, home-schooling.
3. Geographical location of families (from north to south, rural - urban).

THE VOLUNTARY NATURE OF PARTICIPATION

I intend to use a range of methods to recruit mothers. I anticipate these will include three strategies.

- Through personal contacts, as I am part of a whatsapp group (a chat application) consisted of mothers of children with ASD.

- Through the Oman Autism Society: The purpose and the processes of the research will be explained to the Head of the Autism Society and they will be asked to disseminate information about the research to families of children with ASD (see information sheet form below).
- Snowballing: Participants recruited from the above two strategies will be encouraged to inform other mothers about the research project.

I will then personally contact all mothers who express an interest in participating in the project via phone to ensure they understand the purpose and processes of research, are clear about their role in the research and to confirm their willingness to be part of the research. I will also seek written consent from participants (see information sheet and consent form below). Participation will be voluntary. The parent is providing consent on behalf of their child with ASD on the building-rapport day; and parent declare that they will inform and seek the consent of their child for these days as far as is possible, whilst recognising that the child's ASD may impair their capacity for consent.

SPECIAL ARRANGEMENTS

Not Applicable

THE INFORMED NATURE OF PARTICIPATION

The consent form and information sheet (see below) that will be provided to the participants includes information about the aims and the nature of the study. I will translate the information sheet and consent form as I have adequate proficiency in Arabic, and that the Arabic copies of the information sheets and consent forms are faithful translations of their corresponding English forms (see below). Participants will be able to withdraw from the research at any time. The information sheets emphasise that all participation is voluntary and consent can be withdrawn at any time.

At the start of self-constructed story narration, I will explain to them, through the information sheet, that it is their own preference whether to record their oral stories or to write them. I will explain that they are welcome to ask for any data to be deleted after submitting their stories.

At the start of the interviews, I will also seek permission to record the session and explain to them that they can stop the recordings at any point during the session. The interview data will be anonymised on transcription. I will also summarise the key points at the start of each interview. If participants raise any question at any stage of the interview, I will be willing to answer them.

At the start of the building-rapport days I will also seek permission to write notes and explain that they can ask me to leave at any point during the day. The field notes from the days will be anonymised, as with all data. If participants raise any questions at any stage of the days I will be willing to answer them.

ASSESSMENT OF POSSIBLE HARM

ASD may be a sensitive topic for mothers and I will be asking them to tell me about their experience, perceptions and feelings in making educational choices and decisions for their children with ASD. Having a child with ASD can be a very emotional topic for mothers and it is possible that some mothers will find it upsetting to discuss these topics. For this reason, I will have details of counsellors and supporters from the Oman Autism Society that I can refer them to if needed. I have informed a psychiatrist in Al Masarra Hospital about my research, who has agreed to me passing on their details to mothers who may need further support.

All interviewees will be promised confidentiality and their identities will be anonymised. Pseudonyms will be assigned prior to transcription. Any distinguishing characteristics and identities in the interviews will be omitted from the interview transcript and from the stories to ensure that participants cannot be identified from the text.

I have designed for the self-constructed story narration to be completed individually by mothers. They will have their own choice of the time and space to write or tell their stories without the interference of the researcher.

From my own experience as a mother of a child with ASD, I believe that I have a good relationship with other mothers who have children with ASD, so I have an experience in dealing with mothers who may become emotional. I have found that in practice when those mothers are upset it can be useful to move to another more positive topic or offer to pause or stop the interview. I will draw on this experience when interviewing mothers. I will also make sure that interviewees know they do not have to answer any question they do not want to and that they can withdraw at any time.

All of the participants will be female (mothers) and, for the phase 2 interviews, they are likely to request meeting them in their home. This is also the case for phase 3. As a lone researcher, although I am used to meeting people alone, I will need to make some arrangements to ensure personal safety. For both phases, for interviews and for building-rapport days, I will:

1. Inform the driver (a family member) of general (not specific) location details (s/he will drop me off in the locality, not at the specific location to ensure anonymity of the participant), and ensure that s/he has my phone number along with approximate pick up times.
2. Provide a trusted family member with the address of the participant in a sealed envelope, to be accessed only in emergency and if I am not able to be contacted by phone.

DATA PROTECTION AND STORAGE

The printed name and signature on the consent form will be used as an agreement for their participation, but will not be revealed in the research. The consent form will include an explanation of how data will be stored and a written privacy notice. Consent forms will be scanned and uploaded into a separate file on a password protected folder and the original forms will be confidentially shredded. This will also be applied for stories written by participants, which will also be scanned and kept confidentially.

Digital recordings will be deleted as soon as I have an authoritative transcript of the interview or stories narrated by the participants. I will also make sure that the field notes written during the building-rapport days will also include pseudonyms.

After each phase of data collection I will assign pseudonyms of the participants' choice. Participants' pseudonyms and their actual names will be recorded and saved on a password protected spread sheet that will be uploaded onto the university u drive and will not be kept on my home computer or any portable devices. Further details such as names of their children, schools, centres or other people etc. will also be changed and participants' children will be referred to as pseudonyms in transcripts. This is to ensure anonymity to avoid the identification of the participants.

Data that includes confidential details (including contact details) may be kept until my PhD is awarded so that, if necessary, I can contact participants during my PhD. It will be destroyed as soon as my PhD is awarded.

Participants will be assured that their responses will be anonymous and they will only be used for the purpose of this research. Anonymised data will be kept confidential. If I am able to secure funding to have the interviews transcribed then I will remove the identifying details and I will make sure to check and anonymise the transcripts after transcription.

DECLARATION OF INTERESTS

This PhD research is funded by the Ministry of Higher Education in Oman.

It will be clear for the participants that I am working in the Ministry of Education (teacher trainer), but my topic is not related to my profession and I will not be acting in a professional capacity when conducting this research. I do not think that my position at the Ministry of Education will affect mothers' decisions about whether or not to participate, because my profession has no relation to my research. However, it is important that this made clear to them.

USER ENGAGEMENT AND FEEDBACK

Participants will be able to request a copy of their own interview transcript (see information sheet). The self-constructed story narration can be reviewed by the participants as they will give it to me after they are satisfied with their narration, either recorded or written.

In phase three, the building-rapport days, I intend to give participants a copy of the field notes written, so they have the chance to review the written details.

A summary of key findings will be prepared for participants once the research is concluded.

INFORMATION SHEET

This section contains the form that the Oman Autism Society will disseminate to mothers.

Information form (mothers)

Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).

1. What is this project about?

This study is interested in exploring the issues related to Omani mothers educating their children with ASD and their experience, perceptions, feelings with regards the educational choices and decisions for your child with ASD. It aims to understand your experience and feelings about the diagnosis of your child with ASD and your perceptions about the educational services provided by the government. It also aims to understand the strategies you use in order to educate your child with ASD. In particular, it aims to find out the meaning of education from your perspective. Additionally, this research aims to find out whether there are challenges that affect your choice and decision of the education for your child.

2. **Who is conducting this research?**

I am a PhD student at the University of Exeter and a mother of a child with ASD. This research forms part of my PhD and my supervisor is Professor Hazel Lawson h.a.lawson@exeter.ac.uk

3. **What does being part of this study mean for you?**

You have been asked to participate in this study because you are an Omani mother of a child with ASD. There are three parts to the study, you may be asked to participate in more than one phase. Permission will be sought for participation in each phase, using a consent form.

1) Phase 1 will involve you creating a story narration, totally constructed by you without the interference of the researcher as I would like you to feel more comfortable when reconstructing your experience about you and your child. These stories can be oral or recorded.
2) For Phase 2 some story authors, if they volunteer, will be asked to take part in a one-to-one interview with myself. The interview will be face-to-face and likely to last around an hour. It may take place at a venue of your choice. I would like to record this interview with your permission. You can stop this interview at anytime and you do not need to answer any questions that you do not wish to answer.
3) Phase 3 will involve the researcher spending a day with you to get to know you and your situation better. No recordings will be made during the building-rapport day, only written notes which will be shared and can be discussed with you.

4. **How will your data be treated?**

Your real name and the real names of your child will not be used. Every effort will be made to ensure your anonymity.

Your personal data will be treated in the strictest confidence and will not be disclosed to any unauthorised third parties. The results of the research will be published in anonymised form and anonymised data may be saved in a confidential document. The digital recording of your interview will be deleted as soon as there is an authoritative written transcript. Personal and contact details will be stored separately from your interview transcript.

If you request it, you will be supplied with a copy of your interview transcript (please give your email below).

Third parties will not be allowed access to interview transcripts except as required by law or in the event that something disclosed during the interview causes concerns about possible harm to you or to someone else.

5**. Who can I contact for further information?**

For further information about the research or to receive a transcript of your interview, please contact:

Name: Raya Al Raesi
Email: rsa205@exeter.ac.uk

Postal address:
Graduate School of Education
St Luke's Campus
Heavitree Road
Exeter
Devon
EX1 2LU
United Kingdom

Telephone: UK 00 44 (0)7553711098/ Oman 0096899229808

If you have concerns/questions about the research you would like to discuss with someone else at the University, please contact my supervisors:

Professor Hazel Lawson h.a.lawson@exeter.ac.uk
Dr. Alison Black a.e.black@exeter.ac.uk

Information Sheet (to Oman Autism Society)

Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).

1. **What is this project about?**

This study is interested in exploring the issues related to Omani mothers educating their children with Autism Spectrum Disorder (ASD) and their experience, perceptions, feelings with regards the educational choices and decisions for their children with ASD. It aims to understand mothers' experience and feelings about the diagnosis of their child with ASD and perceptions about the educational services provided by the government. It also aims to understand the strategies they use in order to educate their children with ASD. In particular, it aims to find out the meaning of education from their perspective. Additionally, this research aims to find out whether there are challenges that affect their choice of the education for their child.

2. **Who is conducting this research?**

I am a PhD student at the University of Exeter and a mother of a child with ASD. This research forms part of my PhD and my supervisor is Professor Hazel Lawson h.a.lawson@exeter.ac.uk

3. **What is your role in this research?**
I would like the Oman Autism Society to disseminate the information about my research to mothers, who can then they contact me to volunteer.

There are three parts to the study, participants may be asked to participate in more than one phase. Permission will be sought for participation in each phase, using a consent form.

1) Phase 1 will involve participants creating a story narration, totally constructed by them without the interference of the researcher as I would like them to feel more comfortable when reconstructing their experience about participants and their child. These stories can be oral or recorded.
2) For Phase 2 some story authors, if they volunteer, will be asked to take part in a one-to-one interview with myself. The interview will be face-to-face and likely to last around an hour. It may take place at a venue of their choice. I would like to record this interview with their permission. They can stop this interview at anytime and they do not need to answer any questions that they do not wish to answer.
3) Phase 3 will involve the researcher spending a day with participants to get to know them and their situation better. No recordings will be made during the building-rapport day, only written notes, which will be shared and can be discussed with participants.

4. **What should the Oman Autism Society do?**
I would like the Oman Autism Society to disseminate the information form to mothers and then they contact me to volunteer in my research.

5. **Who can the Oman Autism Society contact for further information?**
For further information about the research, please contact:
Name: Raya Al Raesi
Email: rsa205@exeter.ac.uk
Postal address:
Graduate School of Education
St Luke's Campus
Heavitree Road
Exeter
Devon
EX1 2LU
United Kingdom
Telephone: UK 00 44 (0)7553711098/ Oman 0096899229808
If you have concerns/questions about the research you would like to discuss with someone else at the University, please contact my supervisors:
Professor Hazel Lawson h.a.lawson@exeter.ac.uk
Dr. Alison Black a.e.black@exeter.ac.uk

CONSENT FORM

Information and consent form (mothers)

Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).

1**. What is this project about?**

This study is interested in exploring the issues related to Omani mothers educating their children with ASD and their experience, perceptions, feelings with regards the educational choices and decisions for your child with ASD. It aims to understand your experience and feelings about the diagnosis of your child with ASD and your perceptions about the educational services provided by the government. It also aims to understand the strategies you use in order to educate your child with ASD. In particular, it aims to find out the meaning of education from your perspective. Additionally, this research aims to find out whether there are challenges that affect your choice and decision of the education for your child.

2. **Who is conducting this research?**

I am a PhD student at the University of Exeter and a mother of a child with ASD. This research forms part of my PhD and my supervisor is Professor Hazel Lawson h.a.lawson@exeter.ac.uk

3. **What does being part of this study mean for you?**

You have been asked to participate in this study because you are an Omani mother of a child with ASD. There are three parts to the study, you may be asked to participate in more than one phase. Permission will be sought for participation in each phase, using a consent form.

1) Phase 1 will involve you creating a story narration, totally constructed by you without the interference of the researcher as I would like you to feel more comfortable when reconstructing your experience about you and your child. These stories can be oral or recorded.
2) For Phase 2 some story authors, if they volunteer, will be asked to take part in a one-to-one interview with myself. The interview will be face-to-face and likely to last around an hour. It may take place at a venue of your choice. I would like to record this interview with your permission. You can stop this interview at anytime and you do not need to answer any questions that you do not wish to answer.
3) Phase 3 will involve the researcher spending a day with you to get to know you and your situation better. No recordings will be made during the building-rapport day, only written notes which will be shared and can be discussed with you.

4. **How will your data be treated?**

Your real name and the real names of your child will not be used. Every effort will be made to ensure your anonymity.

Your personal data will be treated in the strictest confidence and will not be disclosed to any unauthorised third parties. The results of the research will be published in anonymised form and anonymised data may be saved in a confidential document. The digital recording of your interview will be deleted as soon as there is an authoritative written transcript. Personal and contact details will be stored separately from your interview transcript.

If you request it, you will be supplied with a copy of your interview transcript (please give your email below).

Third parties will not be allowed access to interview transcripts except as required by law or in the event that something disclosed during the interview causes concerns about possible harm to you or to someone else.

5. **Who can I contact for further information?**

For further information about the research or to receive a transcript of your interview, please contact:

Name: Raya Al Raesi
Email: rsa205@exeter.ac.uk

Postal address:
Graduate School of Education
St Luke's Campus
Heavitree Road
Exeter
Devon
EX1 2LU
United Kingdom

Telephone: UK 00 44 (0)7553711098/ Oman 0096899229808

If you have concerns/questions about the research you would like to discuss with someone else at the University, please contact my supervisors:

Professor Hazel Lawson h.a.lawson@exeter.ac.uk
Dr. Alison Black a.e.black@exeter.ac.uk
I have been fully informed about the aims and purposes of the project. I understand that:

- There is no compulsion for me to participate in this research project and,
- If I do choose to participate, I may withdraw at any stage,
- I have the right to refuse permission for the publication of any information about me.
- The information which I give will be used solely for the purposes of this research project, which may include publications or academic conference or seminar presentations,

- Information I give will be treated as confidential; the researcher will make every effort to preserve my anonymity.

....
…..

(Signature of participant) (Printed name of participant)

....
....

(Signature of researcher) (Date)

....

....

(Printed name of researcher)

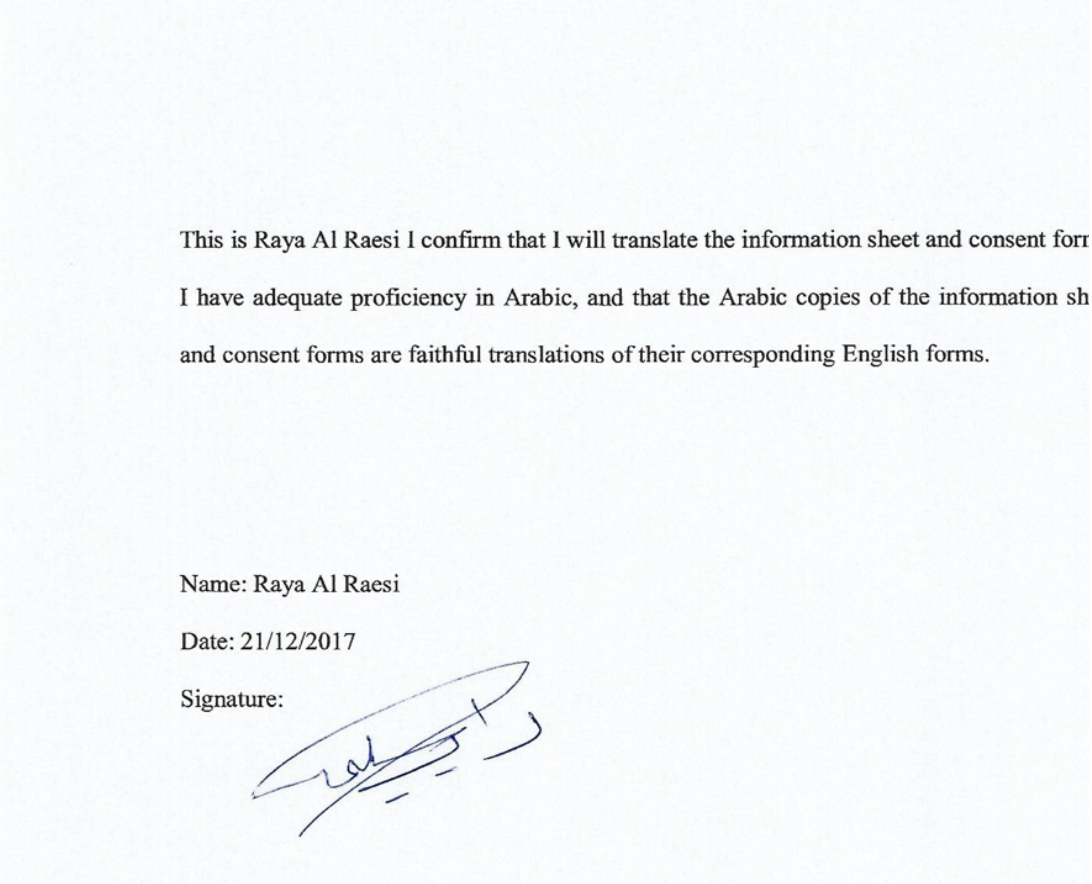
(Email address of participant if they have requested to view a copy of the interview transcript.)

…………………………………………………………….

One copy of this form will be kept by the participant;

a second copy will be kept by the researcher(s).

Your contact details will be kept separately from your data.



This is Raya Al Raesi I confirm that I will translate the information sheet and consent for

I have adequate proficiency in Arabic, and that the Arabic copies of the information sh

and consent forms are faithful translations of their corresponding English forms.

Name: Raya Al Raesi

Date: 21/12/2017

Signature:

SUBMISSION PROCEDURE

Staff and students should follow the procedure below.

Post Graduate Taught Students (Graduate School of Education): Please submit your completed application to your first supervisor. Please see the submission flowchart for further information on the process.

All other students should discuss their application with their supervisor(s) / dissertation tutor / tutor and gain their approval prior to submission. Students should submit evidence of approval with their application, e.g. a copy of the supervisors email approval.

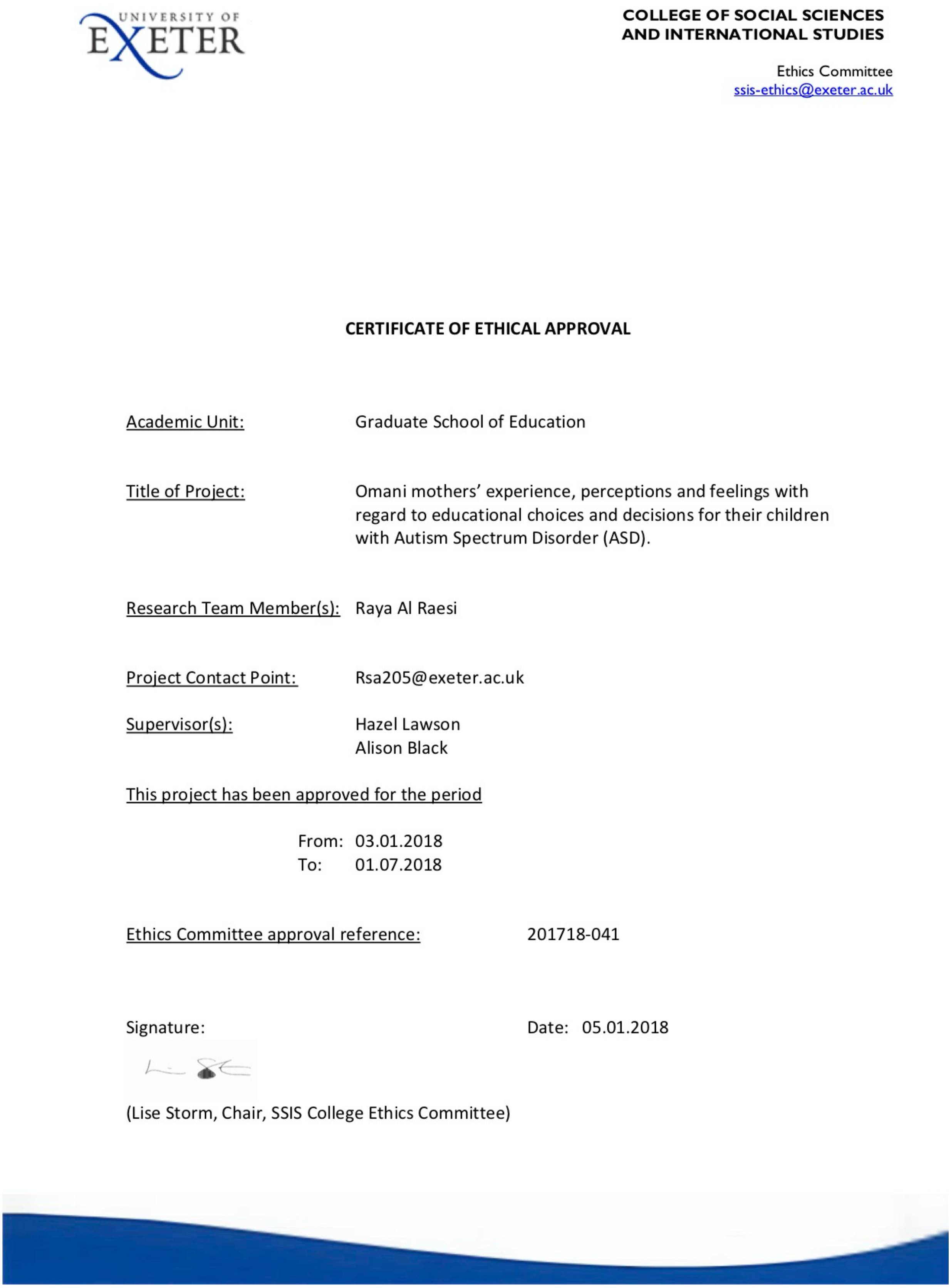
All staff should submit their application to the appropriate email address below.

This application form and examples of your consent form, information sheet and translations of any documents which are not written in English should be submitted by email to the SSIS Ethics Secretary via one of the following email addresses:

ssis-ethics@exeter.ac.uk This email should be used by staff and students in Egenis, the Institute for Arab and Islamic Studies, Law, Politics, the Strategy & Security Institute, and Sociology, Philosophy, Anthropology.

ssis-gseethics@exeter.ac.uk This email should be used by staff and students in the Graduate School of Education.

Please note that applicants will be required to submit a new application if ethics approval has not been granted within 1 year of first submission.



UNIVERSITY OF EXETER

**COLLEGE OF SOCIAL SCIENCES
AND INTERNATIONAL STUDIES**

Ethics Committee
ssis-ethics@exeter.ac.uk

CERTIFICATE OF ETHICAL APPROVAL

Academic Unit:	Graduate School of Education
Title of Project:	Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).
Research Team Member(s):	Raya Al Raesi
Project Contact Point:	Rsa205@exeter.ac.uk
Supervisor(s):	Hazel Lawson Alison Black

This project has been approved for the period

From: 03.01.2018
To: 01.07.2018

Ethics Committee approval reference: 201718-041

Signature:

Date: 05.01.2018

(Lise Storm, Chair, SSIS College Ethics Committee)

Appendix nine: Consent and information sheet & story guide (Arabic version)

UNIVERSITY OF EXETER

تجربة الأمهات العمانيات و تصوراتهن ومشاعرهن في اختيار تعليم ابنادئهن التوحدين

ما هو هذا البحث؟

وتهتم هذه الدراسة باستكشاف القضايا المتعلقة بالأمهات العمانيات التي تقوم بتعليم أطفالهن المصابين باضطراب طيف التوحد والبحث في خبراتهن ووجهات نظرهن ومشاعرهن واستراتيجياتهن عند اختيار التعليم لأطفالهن الذين يعانون من اضطرابات طيف التوحد. ويهدف إلى فهم خبرات ومشاعرهن حول تشخيص طفلك التوحدي وتصورك عن الخدمات التعليمية التي تقدمها الحكومة. كما يهدف إلى فهم الاستراتيجيات التي تستخدمها لتعليم وتدريس طفلك التوحدي على وجه الخصوص، ويهدف إلى معرفة معنى التعليم من وجهات نظرك كام لطفل توحدي. بالإضافة إلى ذلك، يهدف هذا البحث إلى معرفة ما إذا كانت هناك تحديات تؤثر على اختيارك للتعليم لطفلك المصاب باضطراب طيف التوحد.

من القائم على هذا البحث؟

أنا طالبة دكتوراه في جامعة إكستر وأم لطفل مصاب باضطراب طيف التوحد. وهذا البحث يشكل جزءا من رسالة الدكتوراه التي اعمل عليها والمشرفة الاكاديمية على هذا البحث هي الاستاذة هيزل لوسون h.a.lawson@exeter.ac.uk

ماذا يعني بالنسبة لك ان تكون جزء من هذه الدراسة؟

قد طلب منك المشاركة في هذه الدراسة لأنك أم عمانية لطفل عنده اضطراب طيف التوحد. وهذه الدراس عبارة عن ثلاثة أجزاء: قد يطلب منك المساعدة في أكثر من مرحلة واحدة. ولك حرية الاختيار في المشاركة ب واحد أو أكثر من هذي المراحل. وسيلتمس الإذن بالمشاركة في كل مرحلة من مراحل البحث:

1) المرحلة الأولى: هي عبارة عن سرد لقصتك مع طفلك التوحدي، وفي هذه المرحلة ستكون المشاركة فيها من قبلك دون تدخل الباحث لإعطائك فرصة أكبر واريحية في بناء الخبرات الخاصة بك عنك وطفلك المصاب باضطراب طيف التوحد.

2) المرحلة الثانية: سيتم اختيار البعض من المرحلة السابقة وممن لهم الرغبة في المشاركة لإجراء مقابلات فردية معهم. وستكون المقابلة وجها لوجه، ومن المرجح أن تستمر حوالي ساعة. كما سيتم تسجيل المقابلة بعد الحصول على اذنكم. ولكم حرية إيقاف هذه المقابلة في أي وقت، كما لكم الحرية في عدم الإجابة على أي أسئلة لا ترغب في الإجابة عليها.

3) المرحلة الثالثة: وهي عبارة عن زيارة ودية للباحث تشمل قضاء يوم معكم للتعرف عليك وعلى ووضعك بشكل أفضل. لن يتم تسجيل او تصوير اي شيء في خلال اليوم، فقط سيقوم الباحث بكتابة ملاحظات وسيتم مناقشتها معك في نهاية اليوم.

كيف سيتم التعامل مع بياناتك؟

سيتم التعامل مع بياناتك الشخصية بكل سرية

ولن يستخدم اسمك الحقيقي والأسماء الحقيقية لطفلك او لعائلتك. وسيتم بذل كل جهد ممكن لضمان عدم الكشف عن هويتك.

سيتم التعامل مع بياناتك الشخصية بأقصى قدر من الثقة ولن يتم الكشف عنها لأي طرف ثالث غير مصرح به. وسيتم نشر نتائج البحث في شكل مجهول الهوية ويمكن حفظ البيانات المجهولة الهوية في وثيقة سرية وسيتم حذف التسجيل الرقمي للمقابلة الخاص بك في أقرب وقت بعد الحصول على نص مكتوب رسمي من المقابلة الخاصة بك.

سيتم تخزين التفاصيل الشخصية وتفاصيل الاتصال بشكل منفصل عن نص المقابلة ويمكن الاحتفاظ بها لمدة تصل إلى 5 سنوات.

في حلة رغبتك لذلك، فسوف يتم تزويدك بنسخ من المقابلة حتى تتمكن من التعليق عليها وتعديلها كما تراه مناسبا (يرجى إعطاء بريدك الإلكتروني أدناه).

لن يسمح لأي طرف ثالث بالوصول إلى أشرطة المقابلات والنصوص إلا وفقا لما يقتضيه القانون أو في حالة وجود شيء يكشف عنه أثناء المقابلة يسبب مخاوف بشأن الضرر المحتمل لك أو لشخص آخر.

من يمكنني الاتصال به للحصول على مزيد من المعلومات عن البحث؟

الاسم: راية الريسية
البريد الإلكتروني: rsa205@exeter.ac.uk
+٩٩٢٥٩٢٣٤

للتواصل:
كلية الدراسات العليا للتعليم
سانت لوك
شارع هيفيتري
إكستر
ديفون
الرمز البريدي EX1 2LU
المملكة المتحدة
هاتف: 00 44 (0) 7553711098 / 0096899229808

إذا كان لديك مخاوف أو أسئلة حول البحث و ترغب في مناقشته مع شخص آخر في الجامعة، يرجى
الاتصال ب:

بروفيسور هيزل لوسون h.a.lawson@exeter.ac.uk
Dr. أليسون بلاك a.e.black@exeter.ac.uk

الموافقة:

لقد تم إبلاغي تماما بأهداف المشروع ومقاصده. انا افهم هذه الاهداف بشكل واضح تماما:
- ليس هناك أي إكراه بالنسبة لي للمشاركة في هذا المشروع البحثي،
- إذا اخترت المشاركة، اعلم انه يمكنني الانسحاب في أي مرحلة واي وقت،
- لدي الحق في رفض الإذن لنشر أي معلومات عني.
- ستستخدم المعلومات التي أعطيها فقط لأغراض هذا المشروع البحثي، والتي قد تشمل المنشورات أو المؤتمرات الأكاديمية أو عروض الندوات،
- المعلومات التي أعطيها اللباحث سيتم التعامل معها في منتهي السرية؛ سوف يبذل الباحث كل جهد ممكن للحفاظ على عدم الكشف عن هويتي.

اسم المشارك: --
توقيع المشارك: --
توقيع الباحث: --
تاريخ: --
اسم الباحث: --
عنوان البريد الإلكتروني للمشارك إذا طلب من الباحث عرض نسخة من نسخة المقابلة: --- ------ ----------------------------

وسيحتفظ المشارك بنسخة واحدة من هذا النموذج؛
سيتم الاحتفاظ بنسخة ثانية من قبل الباحث.
سيتم الاحتفاظ تفاصيل الاتصال الخاصة بك بشكل منفصل عن البيانات الخاصة بك.

الجزء الأول: البيانات الديموغرافية

القصد منها جمع بعض البيانات العامة عن الامهات وعن اطفالهن مع مراعاة الخصوصية لكل ام وطفلها.

عنوان البحث:
تجارب وخبرات الأمهات العمانيات وتصوراتهن ومشاعرهن في اختيار تعليم وتأهيل أطفالهن المصابين باضطراب طيف التوحد.

تحتوي طريقة جمع البيانات على جزأين. سوف يستغرق الجزء الأول 10 دقائق كحد أقصى.

1. الاسم (اختياري):
....
---------- --

2. عمرك:
20 الى-29-
30 الى-39
40 الى-49
+50

3. عمر طفلك:
3- الى5
6-الى9
10-الى 16
17-الى 18

4. متوسط دخل الاسرة:

منخفض
متوسط
عالي
افضل عدم القول

5. كيف تصف مستوى طفلك من المصاب ابضطراب طيف التوحد
خفيف
متوسط
شديد

6. التعليم الحالي لطفلك
مدرسة حكومية صف خاص بذوي الاحتياجات الخاصة
مدرسة حكومية صف عادي

مدرسة خاصة صف خاص بذوي الاحتياجات الخاصة
مدرسة خاصة صف عادي
مركز الوفاء الاجتماعي
مركز خاص بذوي الاحتياجات الخاصة
تعليم منزلي
تعليم اخر (ارجو ذكر نوع التعليم) -...
7. اعلى مستوى تعليمي وصلتي له:
ابتدائي
اعدادي
ثانوي
بكالوريوس
ماجستير
الدكتوراه
تعليم اخر (ارجو ذكر نوع التعليم) -...
8. الولاية التي تعيش فيها حاليا
....

الجزء الثاني من البحث:
هذا الجزء الهدف منه التعرف على قصتك مع طفلك المصاب باضطراب طيف التوحد

نحن نتحدث عن أطفالنا المصابين باضطراب طيف التوحد لأننا نريد فتح الباب في حياتنا، لمساعدة الآخرين على فهم معنى التوحد، ولرفع مستوى الوعي والقبول عن ابنائنا المصابين باضطراب طيف التوحد.

أنا مهتمة لقراءة او الاستماع إلى قصتك مع ابنك التوحدي. ولك حرية الاختيار في كتابة أو تسجيل قصتك الخاصة. كما ان لك حرية الاختيار في طول القصة على آن تشمل النقاط التالية لتخدم سردك للقصة.

-
طريقة تشخيص طفلك وفي أي عمر؟
- الطرق التي استخدمتها لتعليم طفلك المصاب باضطراب طيف التوحد.
- مدى تطور وتقدم طفلك وطرق التواصل الاجتماعي واللفظي.
- الحديث عن مشاعرك عند معرفتك أن ابنك هو طفل مصاب باضطراب طيف التوحد.
- قراراتك بشأن تعليم طفلك المصاب باضطراب طيف التوحد.
- كيفية تعامل أسرتك وأصدقائه وأخوته.
- التحديات التي تواجهيها فيما يتعلق تعليم طفلك المصاب باضطراب طيف التوحد.
التحديات في الحصول على الخدمات التعليمية والتأهيلية لطفلك المصاب باضطراب طيف التوحد

هل ترغب في المشاركة في مقابلة متابعة؟
نعم

لا

Appendix ten: Consent and information sheet and story guide(English version)

Omani mothers' experience, perceptions and feelings with regard to educational choices and decisions for their children with Autism Spectrum Disorder (ASD).

1. What is this project?

This study is interested in exploring the issues related to Omani mothers educating their children with Autism Spectrum Disorder (ASD) and their experience, perspectives, feelings and strategies when choosing the education for their children with ASD. It aims to understand your experiences and feelings about the diagnosis of your ASD child and your perception about the educational services provided by the government. It also aims to understand the strategies you use in order to educate your ASD children. In particular, it aims to find out the meaning of education from your perspectives. Additionally, this research aims to find out whether there are challenges that affect your choice of the education for your children.

2. Who is conducting this research?

I am a PhD student at the University of Exeter and a mother of a child with ASD. This research forms part of my PhD and my supervisor is Professor Hazel Lawson h.a.lawson@exeter.ac.uk

3. What does being part of this study mean for you?

You have been asked to participate in this study because you are an Omani mother of a child with ASD. There are three parts to the study, you may be asked to help at more than one phase. You may only be selected for one or two of the phases. Permission will be sought for participation in each phase.

4) Phase 1 will involve you creating a story narration, totally constructed by you without the interference of the researcher as I would like you to feel more comfortable when reconstructing your experiences about you and your child.
5) Phase 2 some story authors will be selected to be interviewed. The interview will be face-to-face and likely to last around an hour. I would also like to record this interview with your permission. You can stop this

interview at anytime and you do not need to answer any questions that you do not wish to answer.

6) Phase 3 will involve the researcher spending a day with you to get to know you and your situation better. No recordings will be done during the building-rapport day, only written notes which can be discussed with you.

4. **How will your data be treated?**

Your real name and the real names of your child will not be used. Every effort will be made to ensure your anonymity.

Your personal data will be treated in the strictest confidence and will not be disclosed to any unauthorised third parties. The results of the research will be published in anonymised form and anonymised data may be saved in a confidential document and the digital recording of your interview will be deleted as soon as there is an authoritative written transcript of your interview. Personal and contact details will be stored separately from your interview transcript and may be retained for up to 5 years.

If you request it, you will be supplied with a copy of your interview transcript so that you can comment on and edit it as you see fit (please give your email below).

Third parties will not be allowed access to interview tapes and transcripts except as required by law or in the event that something disclosed during the interview causes concerns about possible harm to you or to someone else.

5**. Who can I contact for further information?**

For further information about the research or your interview data, please contact:

Name: Raya Al Raesi
Email: rsa205@exeter.ac.uk

Oman Autism Society
www.omanautism.om
+96824128949
admin@omanautism.om
@omanautism

Postal address:
Graduate School of Education
St Luke's Campus
Heavitree Road
Exeter
Devon
EX1 2LU
United Kingdom

Telephone: UK 00 44 (0)7553711098/ Oman 0096899229808

If you have concerns/questions about the research you would like to discuss with someone else at the University, please contact:

Professor Hazel Lawson h.a.lawson@exeter.ac.uk
Dr. Alison Black a.e.black@exeter.ac.uk

CONSENT

I have been fully informed about the aims and purposes of the project. I understand that:

- There is no compulsion for me to participate in this research project and,
- If I do choose to participate, I may withdraw at any stage,
- I have the right to refuse permission for the publication of any information about me.
- The information which I give will be used solely for the purposes of this research project, which may include publications or academic conference or seminar presentations,
- Information I give will be treated as confidential; the researcher will make every effort to preserve my anonymity.

Printed name of participant: -------------------------------------

Signature of participant: -------------------------------------

Signature of researcher: -------------------------------------

Date: -------------------------------------

Printed name of researcher: -------------------------------------

Email address of participant if they have requested to view a copy of the interview transcript: -------------------------------------

One copy of this form will be kept by the participant;

A second copy will be kept by the researcher(s).

Your contact details will be kept separately from your data.

Part One: Demographic Data

Omani Mothers' experience, perception and feelings in choosing the education of their children with ASD.

My data collection method has two parts. The first part will take a maximum of 10 minutes.

1. What is your name?

----

2. What is your age? *
    - 20-29
    - 30-39
    - 40-49
    - 50+
3. What is your child's age? *
    - 3-5
    - 6-9
    - 10-16
    - 17-18
4. What is your monthly house-hold income? *
    - Low
    - Average
    - High
    - Prefer not to say
5. How would you describe your child's level of ASD? *
    - Mild
    - Moderate
    - Severe
6. What is the type of education your child attends /receives? *
    - Public mainstream school
    - Public special school
    - Private mainstream school
    - Private special school
    - Home-schooling
    - No schooling
    - Other, (please specify)---------------------------------------
7. What is your highest education level?*
    - Primary degree
    - Secondary degree
    - Bachelor degree
    - Master degree
    - PhD degree
    - Other (please specify)--
8. Where do you live? (Wilayah) *

9. We talk about our children with ASD because we want to open a door into our lives, to help others understand, to raise awareness and build acceptance for children with ASD.

I am interested to read/listen to your story about you and your son. Please use the prompts below as a rough guide and write or audio-record your own story.

It can be as long as you like. Would you please tell me about:

I am interested to read/listen to your story about you and your son. Please use the prompts below as a rough guide and write or audio-record your own story. It can be as long as you like. Would you please tell me about:

- The diagnosis of your child and at what age.

- The ways you use to teach your child.

- Your child's progress (for examples academic, social, communication, life skills).

- Your feelings since the diagnosis of your child.

- Your decisions regarding your child's education.

- Ways your family and friends relate to your child with ASD.

- Experience teaching your child with ASD.

- Experience accessing and using the services and the education for your child with ASD.

10. Would you like to participate in a follow up interview? *

Yes

No

Appendix 11: Participants' demographic data from the story narration phase

No	Name/ age	Child's Name/ age	Gender	Mother's description of child's ASD level	House-hold income	Type of education a child attends	Mother's highest level of education	Whether she will participate in the follow-up interview or not
1	Anfal 20-29	Khamis 10-16	M	Moderate	Average	Public special school	Secondary degree	No
2	Aseel 20-29	Marwan 6-9	M	severe	Average	Public special school	Bachelor degree	
3	Athari	Mostafa 6-9	M	Moderate	Average	Private mainstream school	PhD degree	yes
4	Fadwa 30-39	Afan 10-16	M	severe	Average	Private special school	Bachelor degree	Yes
5	Fatin 20-29	Khozam 6-9	M	severe	Average	Private mainstream school	Bachelor degree in SEN	Yes
		Hassan 3-5	M	Mild		Private mainstream school		
6	Ibtihal 30-39	Yahya 6-9	M	Mild	Average	Public mainstream school	Secondary degree	No
7	Jori 30-39	Mishari 3-5	M	Moderate	Average	Private special school	Secondary degree	No
8	Jumana 40-49	Arif 6-9	M	Mild	Average	Private mainstream school	Secondary degree	No
9	Maha 30-39	Jamal 6-9	M	Moderate	Average	Public special school	Secondary degree	No
10	Mariya 30-39	Adnan 6-9	M	Mild	Average	Private special school	Diploma	No
11	Mayada 40-49	Al Warith 6-9	M	Moderate	Average	Public special school	Secondary degree	No
12	Narjes 40-49	Amjed 6-9	M	Moderate	Average	Private special school	Master Degree	yes

13	Nirmin	AlMolham	Did not provide any demographic data					
14	Njood 30-39	Salman 10-16	M	Moderate	Average	Private special school	Secondary degree	No
15	Rafif	Hatim	Did not provide any demographic data					
16	Rahaf 30-39	Mansoor 6-9	M	Moderate	Average	Private special school	Secondary degree	No
17	Razan 30-39	Khamail 10-16	F	Moderate	Average	Private special school	Secondary degree	No
18	Samaher 40-49	Sami 10-16	M	Moderate	Low	Public mainstream school	Secondary degree	No
		Samiah 6-9	F	Moderate		Home-schooling		
19	Shahad 40-49	Mojahid 10-16	M	severe	Average	Private special school	Secondary degree	Yes
20	Shojoon 30-39	Noor 3-5	F	Moderate	Average	Private special school	Bachelor degree	Yes
		Hoor 6-9	F	Moderate		Private special school		
21	Somood 40-49	Tariq 6-9	M	Mild	Average	Private special school	Secondary degree	Yes
22	Sondos 30-39	Munthir 6-9	M	Mild	Average	Private mainstream school	Master Degree	Yes
23	Thana 40-49	Majed 17-18	M	Moderate	Average	Home No school	Secondary degree	No
24	Zeina 30-39	Obaid 6-9	M	Moderate	Average	Public special school in UK	Master Degree	Yes
25	Zulfa 40-49	Amar 6-9	M	Mild	Average	Private mainstream school	Secondary degree	No

Appendix 12: An example of building-rapport **day**

Monday 16 April 2018:

I arrived home and the housemaid opened the door for me, Noor was the second one to meet. She came to meet me and shack my hands. She was a lovely girl. Noor is the youngest daughter. After two hours, mother arrived. Father was not home because he works 7 days and gets 7 days off.

Noor is the second daughter of Shojoon the first one is Hoor. Noor is non verbal, but her way to meet me showed me that she was sociable and was not afraid of strangers. She was looking into my eyes and she wanted to tell me something.
When mum arrived, the other girl came downstairs. And I met Hoor and her brother Khalil. Shojoon has three children Hoor 8 years old, Noor 4 years old and Khalil 3 years old. The two girls are non-verbal. But they are sociable. They share the same characteristics. They did not feel that I was a stranger though it was my first time to meet them. I felt that the concentration was really good and they have a good eye contact.
The mother trained the housemaid to be careful in very single points like the door keys and not to forgot them in the door so they do not lock themselves.

That night, I did not do a lot because when I arrived it was their bed time and mum did not want to change their routine, so after meeting them they immediately went to bed. The housemaid led me to my room, I was busy texting my family to check my son as he was staying with my mum. Because it was a change for me, I usually struggle to sleep in a different bed. I could not sleep that night and I heard that one of the girls was not sleeping as well. I did not disturb them to check who it was. Everyone slept around three in the morning. Though Shojoon did not sleep well last night because Noor was awake until 3.00. Then Shojoon could not sleep, but she woke up in the morning and prepared the children for the school
Honestly I missed the morning part, because I could not get early. According to Shojoon, she usually prepares Hoor first and then wakes Noor up because Noor usually gets upsets if the bus was late or there was a long time between her getting up and the bus's arrival. So mum tries to shorten the time by waking her up 15 minutes before the bus time. Shojoon recently trained the housemaid to take the girls to the bus as they get upset if she did not go with them in the school bus. According to her, if the girls understand that when their mum wears Abaya, this meant that they would go out and they would refuse to go to school. So she thought that it would be better that the housemaid took them to school and they would think that their mum is still at home. Both girls go to private special school for children with autism. The mother works as a school teacher. So the mother got ready while the housemaid was taking the girls to school bus. Then Shojoon took her son Khalil to the nursery and she went to school. I woke up at 10.00 and went outside wondering the area, because there was no

one at home except of the housemaid and I tried to talk to her, but I could not understand her language.

At 1.15 the girls came from the school and they were active as if, they had a good sleep, though I remember that Noor did not sleep well last night. 2.00. Shojoon arrived from school and she brought Khalil with her. The housemaid changed the children clothes. She took Hoor to the toilet because she is the only one who goes to the toilet, Noor and Khalil are still using nappies.
The housemaid assist the mother in certain points like going to the toilet, but when Shojoon was home, she was taking care of the children. The house was organized in a way that was safe for them so they don't hurt themselves or lock themselves in a room or a toilet. There is nothing that might hurt them in the house and the outdoor was locked tightly. This helped Shojoon to have a balanced life that children were not controlled all the time and she would have time for herself.
I spent most of the time chatting with the Shojoon, and she welcomed me in her house as if she was looking for someone to talk to. We did not have lunch, but she brought some sweets with her. We had some, but the children joined us with the food and they made the place in a total mess, but the housemaid was there to help cleaning up. Shojoon was trying her best to give instruction to the girls, for example Noor took my phone and mum told her in a serious tone to leave it and Noor did. Though there were two girls with ASD in the house, I felt that it was a quite family, there was not lot of crying and shouting. Though Noor was moving around a lot., but it was controlled way. According to Shojoon, Hoor seemed to be quitter today than other days. Noor liked me very much, and she was hugging me from time to time.

As I mentioned before, Noor and Khalil were using nappies, so Hoor was the only one who went to the toilet. She did not ask for toilet and did not show signs for her need to the toilet, but her mum knew her need when she saw her going towards the toilet.
Though the girls were non-verbal and hyper-active going around themselves, they were sociable and were trying to communicate with a stranger like me. We continued chatting with each other while the girls were playing around us and Khalil was watching TV. Sometimes they went out, but mum was sure that they would not go away, because she had safety strategies like locking the outside door.

Hoor likes to play with a tissue, so she cut tissue into small line, and would leave it move with the wind. But because it is tissue and the material is very thin, it was torn easily. This made Hoor upset and she hit her head on the wall with no noise. I could not even notice, but the Shojoon saw her, so she immediately tried to attract her attention to something else.

Both girls were drinking milk from bottle. I am not sure whether Hoor is not drinking milk from bottle, but I saw Noor drinking it.

At 4.30, we went outside the house in the yard and sat for drinking tea and coffee. Hoor and Khalil were inside, while Noor was outside with us and she was using her mum’s phone for 15 minutes only. She was listening to the phone tones and she was not attracted to any other kinds of phone games or youtube. From 4.30 to 6.00, there was not much to talk about and Shojoon was spending much time with me rather than with her children, though they were sitting around us. Sometimes they moved from one room to another, but other than that there was not much. After I left, Shojoon sent me a video for Noor crying and hitting her self. And I asked Shojoon about how she responded to Noor’s tantrum, and she said, she cuddle her and gave her bottle of milk.

Through the day, there was not like time for Shojoon to teach them or train them with certain things. The children were not attracted to the TV though it was switched on all the day. At the same time the phone was in front of the girls all the day, but they were not attracted to it. The housemaid is an assistant for the Shojoon, but the she did not depend totally on the housemaid. Most of the time the girls were around the mum. In the afternoon they spent in the house yard, they play in the games and the mum is watching them.

I was really skeptical that my presence might change the family’s routine, but I felt that they were familiar with people visiting Shojoon. My visit did not affect the girls routine.