

An Investigation into Issues Related to the  
Establishment of a Parental Training Course  
to Develop an Early Intervention Home-  
Based Programme for Children with Autism

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*A Thesis submitted for the degree of Doctor of  
Philosophy*

**By**

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I am happy to acknowledge that the views, interpretation and conclusion, along with any omissions, inadequacies or errors that may remain in this work, are, of course, entirely my own responsibility.

## **Dedication**

*I dedicate this work to*

*Parents of children with Autism who have devoted their time,  
efforts, and love to their children*

*For*

*Those parents who have to face and overcome barriers in order to  
help and support their loved one.*

## Abstract

**Context:** The aim of the proposed research is to investigate autism early intervention in Saudi Arabia, taking into account the reality that such services are in a relatively early stage of development in Saudi Arabia due to the current limited experience in the autism domain generally and in early intervention programmes specifically. As such, this study was intended to act as a basis for gaining a greater understanding about how such services could be developed in Saudi Arabia in the future. Indeed, special attention was given to the cultural specifications to see if such programmes can be implemented and adapted to fit the needs of the families in Saudi Arabia.

**Objective:** The aim is to develop the parental training programme that emerges from parents' needs in relation to their children with autism in which a parental training programme can be developed that leads to the establishment of a home-based intervention programme.

**Method:** The constructivist grounded theory approach used to identify programme components, their implementation and effectiveness. Data collected from (20 interviews, 251 questionnaires, 8 programme evaluation sheets, parental stress index short form (PSI-SF)).

**Results:**

The present study suggested a parental training course framework with a detailed description of its components, delivery approach and evaluation process. This study also provided clear evidence that the current suggested parental training framework targeted the participants' needs and provided them with the support, the information and the skills that they needed at the post diagnosis stage.

**Conclusion:** This result can sensitise services providers in establishing a parental training programme to help empower parents to administer some of the therapies to their autistic children that are needed on a day to day basis, with the minimal amount of stress to the parental life style.

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## Chapter 1: Introduction:

*"Appropriate treatment" is not possible unless and until educators adopt a policy of unfailing respect for the individual. Progress is more important than a cure. Acceptance of difference is more important than achieving normalcy. Tolerance is not good enough because it demands change or at least movement toward an external norm.*

***I deserve acceptance and respect as I am".*** Stephen<sup>1</sup>

*"In the meanwhile, with improved understanding of how many children and adults have ASD, how best to conduct assessments of strengths and difficulties that affect the well-being of children and adults with autism and their families, and what is needed to measure changes in response to treatments, we will be better equipped to develop social policies that aid us in changing the many thing that can be changed for families and children with ASD."*

*Lord & Bishop (2010) p. 16.*

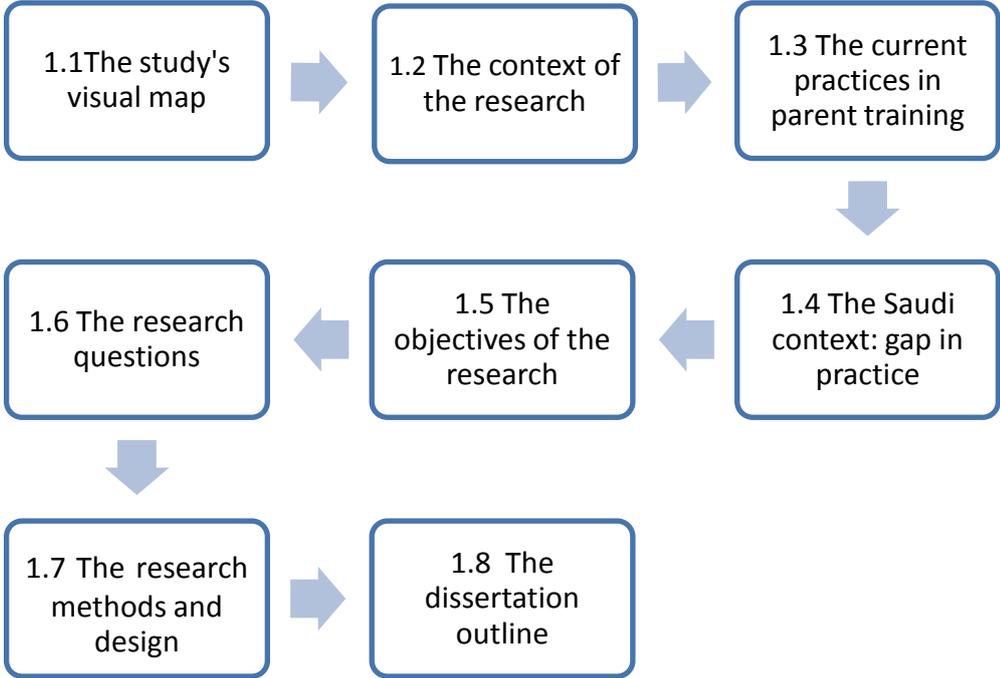
Being an educator and human rights advocate focusing on the rights of disabled individuals, I seek the reward not in myself but by helping others. My mission is to serve my country, Saudi Arabia, in bettering our society by helping the disadvantaged in our society lead in improving their well-being, productivity, and quality of life. Thus, conducting this study in autism is serving my mission to do so. This work will be conducted in my country, Saudi Arabia. This is because of the need to develop research and resources in Arabic, which are presently in short supply both in the study of autism generally and in early intervention research in particular. Therefore, it is hoped that undertaking this study will add to the efforts to improve policies and the services in relation to individuals with Autism and their families.

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<sup>1</sup> Stephen (a gifted and talented 14 year-old who has a mild form of autism called Asperger's Syndrome) <http://giftedgearreview.blogspot.com/>

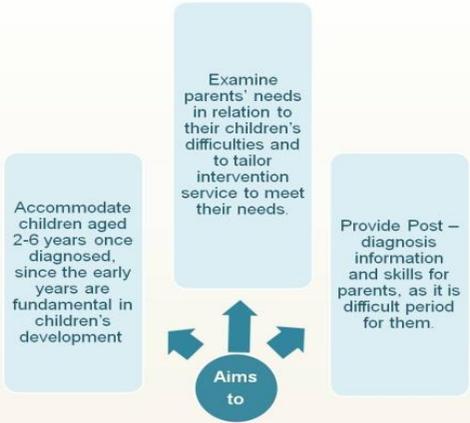
The aim of this chapter is to describe the steps that have been undertaken in order to complete this dissertation in the field of autism. Therefore, a visual map is warranted as a starting point since it helps to clarify the research framework. Firstly, this introduction will highlight the context of current research. Secondly, this would be followed by a perspective of current practice in parent training. The third will discuss the current practices in parental training programmes. The fourth section will highlight the historical aspects of autism services within the Saudi context. This will be followed by an illustration of specific objectives and research questions in the fifth and sixth sessions respectively. The seventh section will consider the research methodology appropriate for collecting the research data. Finally, the dissertation outline will be provided.

Figure 1 Structure of Chapter One



# 1.1 The Study's Visual Map:

## Study Aims



## Study Importance



## Methodology

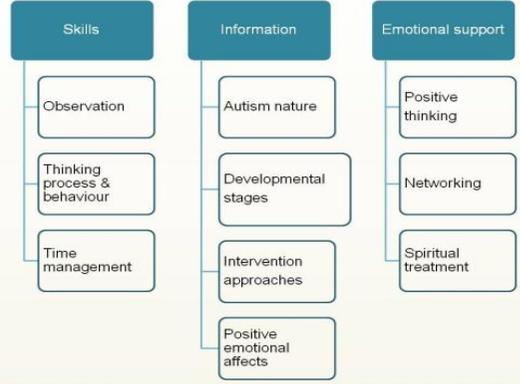
**How should a parental training programme be developed within the Saudi context?**  
The grounded theory approach is being applied to analyse data collected using multi-methods as follow:



## Interviews and Questionnaires outcomes



## Programme components



## Programme implementation /evaluation



**Result:** Feedback provided by the mothers showed their satisfaction with the programme components and implementation. However, mothers stress level was high pre and post training which suggest further investigations.

## **1.2 The Context of the Research:**

### **1.2.1 Personal Motivation:**

The aim of the proposed research is to identify how a parental training programme for children with autism should be developed within the Saudi context. The research will be written from the perspective of an author who is a special education teacher by profession. Indeed, following a substantial reflection on my working experience as a special education teacher working with individuals with autism and their families in Saudi Arabia, I can utilise my position by relating everyday experiences and observations with families to develop a parental training programme which focuses on a home-based early intervention for individuals with autism. Under the current circumstances and the availability of the current services in Saudi Arabia, this development, in my opinion, is considered to be essential.

In fact, several factors have motivated me to research this area: Firstly, early intervention programmes for individuals with autism are in a relatively early stage of development in Saudi Arabia due to the current limited experience of the autism domain generally and in early intervention programmes specifically. Secondly, there is the importance of working with children at any early age in their development. Thirdly, the role of parents in their child's development is crucial in general, and in the child with special needs in particular. However, parenting a child with a special need such as autism is very demanding. Therefore, parents need specific skills in order to be able to help their child effectively. The current training programme will focus on providing caregivers with the necessary information and skills that they would need to develop an early intervention home programme.

### **1.2.2 Study Rationale:**

Autism is a life-long developmental disorder affecting individuals and their essential human behaviours that include social interaction and relationships, communication and thinking flexibly. These three main areas are known as

a triad of impairments. Individuals who are diagnosed as having autism are thus unlikely to develop normally and so will be at a considerable disadvantage in comparison to others. Moreover, parenting a child with such difficulties is not an easy task. Indeed, for many, the ‘parental journey’ that they need to undergo encompasses specific phases. The first phase is the suspicion phase which consists of suspecting that their child might have a problem. This may be followed by the second phase which is the diagnostic phase, in which the parents seek medical advice, followed by a diagnosis confirming the existence of an autistic spectrum disorder. The final phase concerns accepting the diagnosis, in which the parents must come to terms with their child’s disorder and its ramifications.

These phases could also be applied more generally, for example, if someone was to be diagnosed as having diabetes after suspecting he or she had a problem, then the person would be likely to undertake specific therapy to tackle their diabetes. Similarly, it is possible to think about a child with autism in the same way, and this leads to the conclusion that in each of these phases the parents need professional support and help. In this study the focus of attention will be directed towards the final phase, which is how the parents may most effectively tackle their child’s problem following a diagnosis of autism.

This stage is extremely crucial, not only for the parents but also for the child’s further development and future. Caregivers need to acquire specific skills in order to meet the child’s special needs. Such skills include being prepared to accept the child as he/she is and loving him/her regardless of the disability. Being aware of the nature of autism and how it might considerably affect the child’s development, is also important, as is becoming educated about the kinds of intervention available for such individuals and maintaining an up-to-date knowledge of the latest developments in the autism field. A further skill is becoming aware of the importance of the parental role in their child’s continued development and how to adapt to the reality of such a disability. However, it is likely that

many parents could find it difficult to accommodate their child's needs and balance those with their other responsibilities and duties without the support and help from specialist professionals. In fact, a parallel can be seen here with the above diabetic therapy plan, as given by a physician to diabetic patients to allow them to adapt to their disease.

Indeed, as an educationalist reflecting on my experience of working with individuals with autism and their families, I believe that professionals and parents might have different perspectives about the skills that parents might need to accommodate their child's needs. This could be due to several reasons. An example of one such reason is the variation in their roles and the position that each individual plays within the autistic child's life. For instance, what a parent may want for and expect from their child could be substantially different to that from a professional opinion. Similarly, although both parents and professionals might experience stress when dealing with the child, the stress levels vary. Perhaps this stems from the fact that professionals deal with the child as 'a case' and within a specific time frame, whereas the parents play a special part in the child's dynamics as they are a part of the child's daily life. According to a study conducted by Dale (2006), the mothers of children with autism had significantly higher stress levels on a parental stress index in comparison to the parents of normally developing children. Accordingly, a consideration of parental perspectives could help in designing an effective training programme, and training that can help to reduce the stress levels.

It could be anticipated that when parents seek help and advice from professionals, they might have specific requirements or certain ideas about what they want. Therefore, within this study, the investigation will attempt to identify in novice parents what the parents think, feel and expect. The investigation will also attempt to establish the reasons behind why the parents search for consultation and to discover what the parents *want and expect* of the professionals as well as to what extent they *receive* professional help and advice. Based on the parental data and perspectives,

such data might help to identify suitable components a parental training programme should include which would help the parents acquire the essential knowledge and skills that they need to develop a home-based early intervention programme. Thus, the main aim of this study is to develop a parental training programme which examines the parental perspectives about existing services and the practical support and help which the parents may optimally expect professionals to provide for them immediately following the diagnosis of autism.

### **1.3 Current Practice in Parent Training:**

Parental training is a type of service that is provided under the umbrella of early intervention provision. Such a service aims to equip the caregivers with the necessary knowledge and skills that they need to enhance parental confidence in helping their children. An early intervention programme has the same general special education aim in targeting individuals with autism, in both educational and clinical needs. Indeed, an early intervention's main focus is part of the special educational provision practices, which is to provide services that accommodate the children with autism and their families by providing them with the psychological and educational support that they need at the post-diagnosis stage (Shields 2001). Previous initiatives have defined the purpose of an early intervention program as a means to help facilitate the children with therapies to remedy the current developmental problems, in order to stop its re-occurrences and to provide the families with an action plan in order to help these children (Perry et al., 2008). In fact, special educational provision for individuals with autism is considered to be at the top of the interventions list that is available for people with special needs (Reed et al., 2007). Generally, the aim of this provision is not only to offer effective learning opportunities that meet the individual's needs, but is also a remedial goal, by addressing the triad of impairment in autism and to try to reduce its resultant problems from being manifested clearly in the child's behaviours (Jordan, 2002).

Thus, the shortages in providing early intervention services for children with autism and their families has increased and the call for such services has been documented worldwide in the literature (Nefdt et al., 2010; Shattuck and Grosse, 2007; Dymond et al., 2007; Ingersoll and Dvortcsak, 2006). The increasing prevalence of autism occurrences is one of the reasons behind the increased demand on such services (Rice et al., 2010). Recent statistics showed an increasing incidence of autism spectrum disorders (King and Bearman, 2009; Knapp et al., 2009). For example, in the UK, according to Baird and colleagues (2006) 1 in 100 individuals are autistic. In the USA, Hertz-Picciotto and Delwiche (2009) reported that there is an increased incidence of autism amongst children under the age of 5 years old, from 6.2 for 1990 births to 42.5 for 2001 births. This can be contributed to the fact that there is an increase of early detection of autism signs before the age of three which has become a current trend within the field (Cassidy et al., 2008).

However, upon examining the literature, it has shown that there is a gap in the policy and the practice related to early intervention programmes (Turnbull et al., 2007). The reason for this phenomenon has been related to the fact that the vast majority of early intervention programmes studies have focussed on programme effectiveness and child outcomes (Grindle et al., 2008; Turnbull et al., 2007) ; therefore, there is a limited understanding of what support and services should be provided for families with children who have disabilities (Webster et al., 2003), especially since the parents might develop their own adaptation to the system based on their personal knowledge and understanding of their own child (Keilty and Galvin, 2006). Thus, the successful implementation of family interventions required a consideration of their needs (Kling et al., 2010; Meirsschaut et al., 2010). Consequently, this study's intention is to fill a gap in the understanding of the development of a parental early intervention training programme within the Saudi context, by giving specific consideration to the parental perspectives.

## **1.4 Saudi Context: Gap in Practice<sup>2</sup>**

As the focus of this research lies within the Saudi context, it is imperative to highlight the historical significance of this initiative in order to understand the current state that many of the participants are living under. The historical aspect of the autism centres in Saudi Arabia began with the initiatives from a few caring individuals with autistic children. Saudi Arabia's autistic early intervention programme is still in its infancy stage. The first centre for autism was established in 1993 by a group of private individuals. After that the government started to facilitate and establish government sponsored programmes or educational services in 1998; the first of which were educational programmes attached within special educational institutes in Saudi's main cities, Riyadh, Jeddah, and Dammam. Following that, in 2004, the first governmental autism centre was established in Jeddah. Then, the first government centre for both diagnostic and early intervention was opened in Jeddah in 2007. Recently, the first Scientific Forum of Autism Centres in the Arab world, held under the support of the Arab Gulf Program for United Nations Development Organizations (AGFUND), took place in November 2008. Saudi Arabia is trying to find ways to cope with the growing number of autistic children; both early intervention programmes and parental training courses are limited, and only infrequently provided in Saudi due to the shortages of specialised people and facilities. This study is a step towards developing and offering home-based early intervention services for both children and their parents within

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<sup>2</sup>Since the focus of the dissertation lies within the Saudi context, it is felt that it is important to acknowledge that both Arabic and English references were used in writing this current dissertation. Therefore, consulted references that were in English would be referenced following the style that is expected for referencing in a UK thesis. On the other hand, references that were originally written in Arabic were also consulted, such as references including theses, books articles and Saudi governmental websites. The same referencing process was given to the Arabic originals, and then the titles were translated into English by the researcher. Moreover, the Qur'an and Hadith verses were translated into the English language and referenced. Indeed, most of the Arabic references that were translated into English references were used in Chapter two, the Saudi context.

the Saudi context, in order to deal with the growing demand for a care network for the increasing number of autistic individuals.

Despite the governmental effort to offer services for individuals with autism and their families, one should consider that the autism domain in Saudi is only eighteen years old, which explains the limitation and shortage of qualified specialized staff and facilities needed to establish early intervention programmes and parental training courses in Saudi Arabia. Moreover, scientific studies that aim to develop or to evaluate educational provision effectiveness on both child development and family outcomes are rare in nature, especially since the focus goes towards offering services, rather than developing or evaluating them. Indeed, the previous discussion of the history behind the development of the autism centres gives a justification for the current study's aim and its significance, as the results of this study might help in shaping steps towards developing and offering intervention services, for both children and their parents. Thus, this would lead the discussion toward the importance of such an investigation within the Saudi context.

#### **1.4.1 The Study's Importance**

As discussed earlier the role of the parents in their child's development is crucial in a general context, but even more so in the case of a child with special needs in particular. However, parenting a child with a special need, such as autism, is very demanding. Therefore, the parents need specific skills in order to be able to help their child effectively. Indeed, parental training programmes could be seen as a helpful option that might equip the parents with some skills and knowledge that they need in order to be able to parent their child as effectively as possible. However and to the best of my knowledge, most of the training that is offered for parents in Saudi is conducted in the form of lectures or in one or two day workshops, whereas comprehensive parental training programmes are limited and rarely provided. Moreover, there is absence of studies that have been undertaken into parental training programmes that lead to early intervention home-

based programmes in Saudi Arabia. This consideration is particularly important as it would also take into account any particular cultural specificity.

Other important factors for working with children at an early age in their development are the limited availability or the quality of the services. First, due to the centres' limited class capacity, the number of children who are receiving educational intervention in their early years is minimal compared to the number that is on the waiting list.

Intervention intensity is another issue that needed to be considered within the available centre-based early intervention programmes, as children usually only spend three hours a day at the centre. This means that the child receives only fifteen intervention hours weekly, which is less than most research results indicate that a child with autism should receive weekly (Noyes-Grosser et al., 2005; Lovaas, 1993). Again, at this point parental involvement could be seen as essential in order to provide the children with the school-like intervention program to be continued at home in order to help meet the recommended amount of weekly intervention, in accordance with research findings.

Finally, parental involvement in their child's intervention help parents to become aware of their child's individual educational plan more than developing or generating plan objectives. Indeed, it could be anticipated that this minimal involvement might be a result of the parents' lack of knowledge or confidence in the significance of their role in their child's development. Another issue is that professionals might underestimate the caregivers' ability to implement intervention effectively with their children. All of the previous discussions highlighted the concerns into the motivational basis in which the issues were researched in relation to developing a parental training programme that may lead to establishing a home-based early intervention within the Saudi context.

### **1.4.2 Justification of Benefit**

The importance of such a training programme in Saudi Arabia can be summarized as follows: firstly, consideration of the parental perspectives might give a clearer picture of the content of a parental training programme, as these are based on the parental needs. Secondly, giving an opportunity to the parents to express and identify their needs might enhance their confidence and reduce their stress levels about the decisions they should make regarding their child's future. Additionally, providing the parents with the skills and support that they think they should receive might motivate them to learn and acquire the new skills. Fourthly, offering such a training programme might help in building the parents' basic skills that they need to acquire at this stage. Moreover, it is suggested here that such skills and knowledge will endure and parents could build on them as the child develops. More importantly, the training programme would target the 'novice' parents about autism as early as possible, which could help in accommodating young, recently diagnosed children at home until they could receive school intervention. This would maximise the chances for the child to be exposed to early intervention at home.

### **1.5 Research Objectives**

The training programme would target the 'novice' parents about autism as early as possible which could help in accommodating the young, recently diagnosed children at home until they could receive school intervention. This would in turn, maximise the chances for the child to be exposed to early intervention at home. Thus, this exemplifies the study's main goal in examining issues related to the development of a parental training programme that would lead to an early intervention home-based programme. From this focus the following objectives were generated in order to accommodate the children as early as possible.

- To accommodate as early as possible, the recently diagnosed autistic preschoolers (aged 2 to 6 years) whose severity level is mild to moderate.

- To explore the parental impact of the diagnosis, concerning having an autistic child, and to identify which factors generate a more stressful scenario.
- To evaluate parental knowledge, their approach, and their empathy towards the autistic child.
- To develop a parental training programme based on interview findings, questionnaire findings, and current knowledge within the autism domain.
- To execute the parental training programme by equipping the parents with the knowledge and skills needed to implement an effective home based intervention programme.
- To explore the effectiveness of a parental training programme based on the confidence on how the parents approach the task of providing education for their child.

## **1.6 Research Questions**

The study has been guided by a key research question and five sub-questions as follows:

*‘How should a parental early intervention training programme be developed in the light of parental understanding of autism nature and the parental role in the child’s development within the Saudi context?’*

Further issues arise here which require consideration in order to answer the main study question. Within the main question, there are several areas which have been explored and these are:

- ✓ How might a parental training programme be developed?
- ✓ What should the programme components be comprised of?
- ✓ How might a parental training programme be run?
- ✓ What intervention strategies are more effective and are suitable to be implemented with an age group of between two and six years?
- ✓ How could programme effectiveness be evaluated?

## **1.7 Research Methods and Design**

In the light of the research questions, it is felt that a qualitative grounded theory approach would be the best to use in this study. Such an approach focuses on meanings and understandings in natural situations (Silverman, 2010). Creswell (2003) describes the qualitative approach as a flexible systematic procedure which follows a 'post-modern' way of thinking which gives the researcher the opportunity to reform the research questions and change the data collection process whenever it is necessary, especially when researchers are the primary instruments for data collection. In addition, the ways that the researchers collect and analyse data reflect how they are sensitive to these data and how the findings shape the overall study.

Thus, this dissertation will investigate, describe, explore and explain the development of a parental training course designed to establish a home-based early intervention programme for individuals with autism in Saudi Arabia. The research approach will use the grounded theory in order to identify the programme components, their implementation and their effectiveness. Conducting a grounded theory approach gives the researcher the privilege of being exploratory, sensitive, flexible and yet systematic when examining particular human experiences within its natural setting (Punch, 2009; Chenitz & Swanson, 1986). Goulding and colleagues (1999) argued that test or verified theories might not be as explicit and sensitive to human problems as qualitative approaches such as grounded theory. Because the case for this study focuses on the examination of the parents' needs in relation to their children with autism and comprises the difficult human experiences that are explored and reflected upon, the ground theory approach was considered to be the most appropriate method of research.

The adopted Constructivist Grounded Theory methodology could be defined as a way of generating and building theory from the existing data that has been gathered and analysed systematically (Silverman, 2004; Flick, 2002; Strauss and Corbin, 1998). Indeed, theory generation is the process of

testing emerging ideas against data (Silverman, 2004), where the researcher treats each piece of data as one unit and reflects on each step in the light of the whole research process. Flick (2002) values this ‘circulation procedure’ as a strong and central feature of the grounded theory. Therefore, this methodology would offer the opportunity to develop a conceptual framework about the experiences of study population. Strauss and Corbin (1998) stated that when a theory is not available to explain how people experience phenomena a grounded theory is a best framework to use.

The current investigation, following the constructivist grounded theory approach, was conducted in three phases. Phase one was the pilot study that attempted to gain a greater understanding about how early intervention programmes for individuals with autism in Saudi Arabia could be developed. The collected evidence within this phase directed the research to what information needs to be acquired and from whom. Therefore, within the second phase, both self-completed, open-ended questionnaires and semi-structured open-ended interview questions have been devised as data collection instruments to fulfil the research objectives. These objectives were: examining the parents of individuals with autism experiences, before and after seeking the autism diagnosis; the parents’ ability in identifying their child’s difficulties; the parental perspective within the family roles in the child’s life; and the support that the family and the child have received. As a result, two groups of parents of children with autism were represented in the research sample. The first group was the open sample that was based on a larger, more diverse, and more representative sample with no inclusion conditions. The second group was the selective sample, which was limited to novice mothers who have a child newly diagnosed with autism within the mild to moderate continuum of the autism spectrum, between the ages of 2 and 6. Twenty novice mothers were the main study sample who have been interviewed and were asked to participate in the training programme. After that, the immediate and on-going mothers’ needs have been identified through a constant comparison of similarities and differences between the interview and the questionnaires’ findings. This has in turn helped in

determining the parental training programme's components and its design. Thus, the previous phase has led to the third phase of this investigation, which was the implementation and subsequently the evaluation of the current programme. The programme has been designed to be conducted over a six week period, to cover five main sessions. There was a total of 24 intervention training hours that were given twice a week for two hours a day.

Concerning the training evaluations, two methods have been applied to evaluate the training programme: the evaluation forms that have been developed by the researcher and the PSI/SF (parent stress index short form). The evaluation has aimed to assess the programme components and the usefulness of the delivery approach to the participants, and to ensure that it is beneficial to the mothers and helps to meet their expectations in terms of the information, skills and empowerment that they need. The overall result has suggested a parental training course framework with a detailed description of its components, delivery approach and evaluation process.

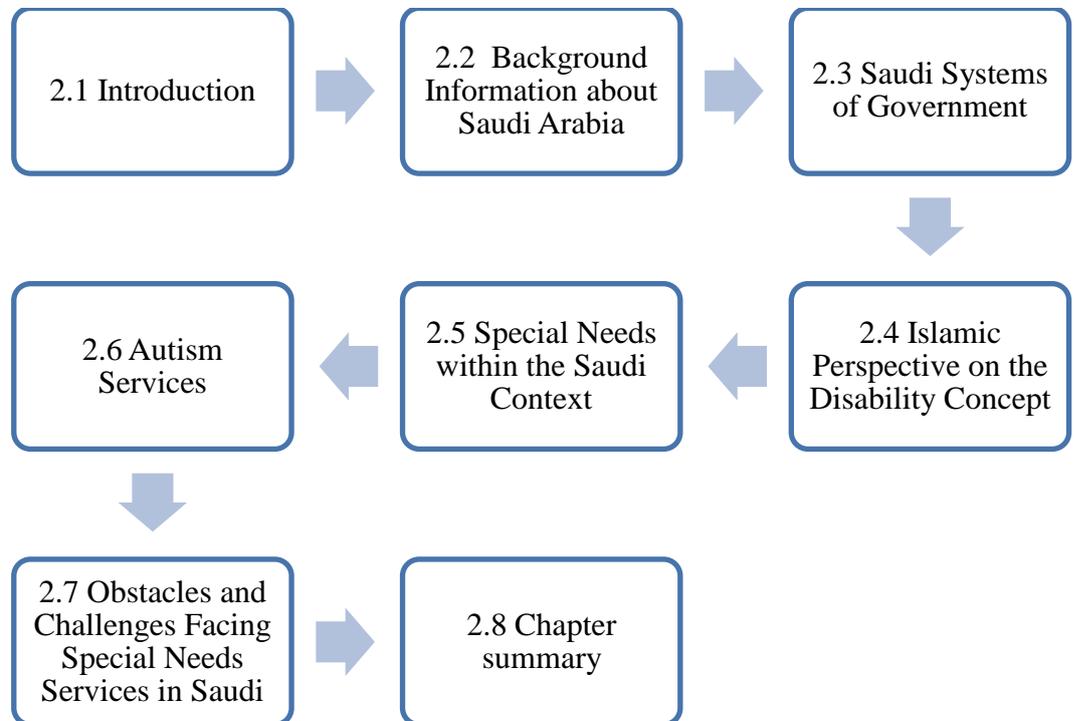
## **1.8 Dissertation Outline**

The dissertation is divided into six main chapters along with this chapter. Chapter 2 examines the Saudi background in order to provide an in-depth preview about the most influential factors that affect the development of the special need services (general and autism services), particularly in the Saudi context as this is where this study has been conducted. Chapter 3 comprises the relevant academic and professional literature in relation to three major areas associated with the establishment of a parental training programme in order to develop an early intervention home-based programme. Chapter 4 discusses the research paradigm used for this thesis, as well as giving a brief overview of the grounded theory approach and how it applies to this research. Chapter 5 highlights the analysing and coding stages of the interview and questionnaire findings within the context of constructing grounded theory protocol. Chapter 6 describes the process of designing, implementing and evaluating the training programme, and also discusses the

outcomes and implications of applying such a programme. Chapter 7 discusses the study's main findings in relation to the literature and in the light of the results' implications and limitations.

## Chapter 2: The Kingdom of Saudi Arabia

Figure 2 Structure of Chapter 2



### 2.1 Introduction

The main objective of this dissertation is to develop the parental training programme that emerges from the parents' needs in relation to their children with autism. This study will be conducted in Saudi Arabia, thereby highlighting the different aspects of the Saudi culture with a special emphasis on examining the Islamic perspective as one of the important influential factors that shape the culture. Indeed, this chapter will take an in-depth look into the Saudi culture and background, because it is essential to provide background information about Saudi Arabia (overall demographics), Saudi systems of government (governmental sectors and Islamic law), the Islamic perspective of the disadvantaged, and the development of special needs in Saudi Arabia, the autistic services available, and challenges and obstacles for special needs services in Saudi

Arabia. Providing the reader with a clearer picture and deeper understanding about the study context is necessary because providing an account of the principles and practices of Islamic and governmental law is essential for helping to understand how educational provisions are shaped.

## **2.2 Background Information about Saudi Arabia**

The Kingdom of Saudi Arabia is located in the heart of the Middle East and the Islamic world. The north of the country is bordered by Jordan, Iraq and Kuwait; the east is bordered by the Gulf, Bahrain, Qatar and the United Arab Emirates; the south is bordered by the Sultanate of Oman and Yemen; and the west is bordered by the Red Sea. It comprises almost 80% of the Arabian Peninsula, and therefore, is considered to be the largest country in the area. The Saudi population is about 27,136,977<sup>3</sup> 3 million people, of which 8 million are non-nationals. The country consists of thirteen provinces. Saudi's main cities are Riyadh (the capital), Jeddah (the port and Saudi's second biggest city), Makkah and Madinah (the two holy Islamic cities) (see Figure 3).

Saudi Arabia is an Islamic Arab state that has a constitution based on the Holy Qur'an. Saudi Arabia is deeply rooted in Arabic culture which is reflected in its identity. The national language is Arabic; however, the business language that is used is English.

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<sup>3</sup> <http://www.cdsi.gov.sa/english/>

Figure 3 Map of Saudi Arabia

Source <sup>4</sup>



Table 1 Economic Indicators for Saudi Arabia

Source: economy watch <sup>5</sup>

Saudi Arabia in 2008	Indicator Values
GDP (Constant Prices, National Currency)	SAR 872.675 Billion
GDP Growth (Constant Prices, National Currency)	37.44%
GDP Per Capita (Constant Prices, National Currency)	SAR 33,428.17
GDP Per Capita (Current Prices, National Currency)	SAR 63,649.20
GDP Per Capita (Current Prices, US Dollars)	US\$ 16,995.78
Inflation (Average Consumer Price Change %)	5.354 %.
Population	26.106 Million
Current Account Balance (US Dollars)	38.792 Billion
Current Account Balance (% GDP)	8.743 %

<sup>4</sup> <http://www.saudinf.com/main/map.htm>

<sup>5</sup> <http://www.economywatch.com/economic-statistics/country/Saudi-Arabia/>  
<http://www.cdsi.gov.sa/english/>

Table 2 Government Expenditures  
Source 6: Earth trend (2003)

Saudi Government Expenditure	Percentage of the GDP
<b>Military</b>	11.6%
<b>Public Education (1996- 1998)</b>	7.5%
<b>Public Health (1997)</b>	6.4

Saudi Arabia is considered to be the largest exporter of oil since its discovery in the 1930s, because Saudi has more than a quarter of the world's proven oil reserves lying beneath its land. Since discovering oil, Saudi has experienced an enormous growth and development over a short period of time, and this has resulted in a high standard of living for Saudi citizens. Thus, the discovery of oil has played a large role in the Saudi economic and industrial growth and is the major source of the economic income. Tables 1 and 2.respectively highlight the economic indicators and government expenditure for Saudi Arabia.

## **2.3 Saudi Systems of Government**

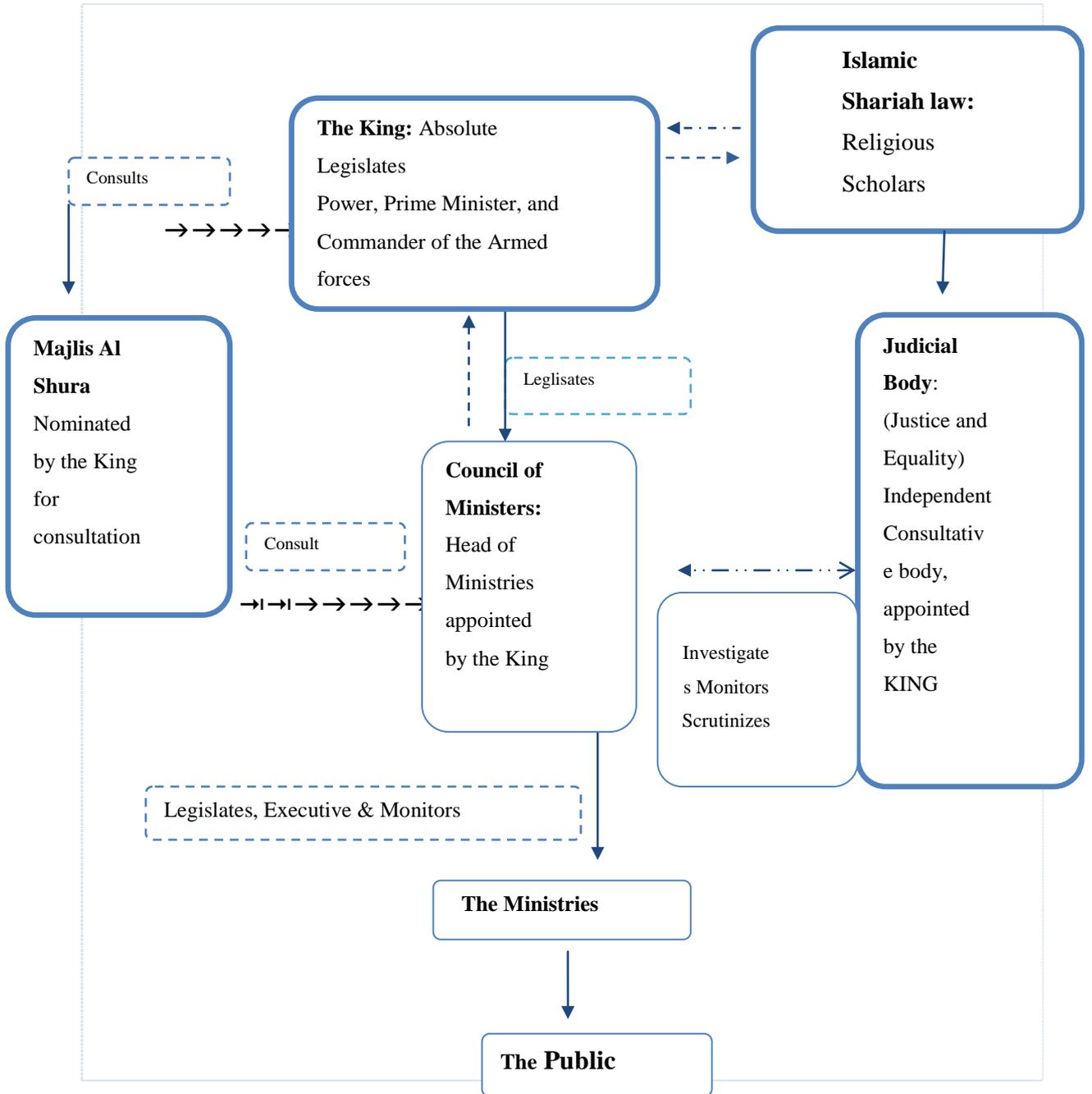
### **2.3.1 Political system**

The Saudi government is a monarchy which is headed by the King and the Crown Prince (second in line to the throne). Therefore, the King, who is the acting Prime Minister, governs with the assistance of the Council of Ministers and on the advice of the Consultative Council. The Council of Ministers is the final authority for internal and external affairs and consists of twenty-two ministries. The Consultative Council consists of 150 members whose duty it is to propose new laws and modify existing ones.

Figure 4 shows the constitutional relationship of these parties within Saudi Arabia.

Figure 4 Constitutional Relationships in Saudi Arabia

Source: Compiled by the author.



### **2.3.2 Islamic Influence on Legislation**

As stated earlier, Islam is regarded as an important, powerful factor on shaping Saudi legislation. The following section defines Islam and identifies how it influences Saudi legislation.

Islam means "submission". Muslims believe one should be surrendering to God's will by complying and obeying the laws and commandments of God. These laws are based on the belief that there is no God but Allah, and Mohammed is His messenger.

Saudi Arabia is considered as an Islamic country based on the fact that its political system generates its rules of law and regulation from "the Shariah laws". The Shariah laws are based on two sources of jurisprudence: the Holy Qur'an (Muslims' Holy book) and the Sunnah (Prophetic Traditions). The Holy Qur'an is the first Islamic source of religious jurisprudence. To Muslims, the Qur'an is believed to be the direct word of Allah (Islamic name for God) revealed to the Prophet Mohammed via the Angel Gabriel. The second source of Islamic religious jurisprudence is retrieved from the Sunnah (Prophetic Traditions) which is the "*hadith*" - the Islamic narratives based on the anthology of the Prophet Mohammed's teaching, actions, sayings, virtues, opinions and ways of life. It is an ideal implication of implementing Qur'an verses into practice (Morad et al., 2001; Hasnain et al., 2008). Indeed, the Qur'an stated clearly that the Prophet is not only the messenger of Allah but he is also a teacher at the same time, "*just as we have sent among you a messenger from yourselves reacting to you and teaching you the book and wisdom and teaching you that which you did not know*" (Chapter 2, Verse 151).

### **2.3.3 Historical Accounts**

Islamic philosophy holds a positive attitude towards needy individuals and those who are in a disadvantaged situation. The Qur'an and the hadiths not only declared the existence of disabilities as a natural part of human nature

but also provided the principles for caring about them and the significance of such caring. Even though establishing and providing caring services for needy individuals throughout fourteen centuries by the Muslims' efforts is not this study's aim, it does, however, provide some examples which might give the reader a snapshot of the existence of such efforts since the beginning of Islam. Thus, such exploration into Islamic history may provide some enlightening facts that will help develop the understanding of the current situation.

Searching Islamic history, many examples of early Muslim influential figures or role models have illustrated the manner of caring for disadvantaged people and including them within the society. One such role model is Umar bin Al Khattab, the third Muslim leader<sup>6</sup> who provided a blind man with housing near the mosque after the father of the disabled boy complained to Umar about his son being unable to reach the mosque. Another example is in 707AD, Al-Walid ibn Abd Almalik, an Umayyad leader, established the first estate for 'mentally retarded' individuals. Then, in 765AD, he built the first hospital which accommodated the 'feeble-minded' as part of its services. Al-Walid also assigned each disabled and needy individual a caregiver (Aljazoli, 2004). Another influential Islamic leader was Umar ibn Abd al Aziz, another Umayyad leader, who ordered a census to be conducted of the number of disadvantaged people in his era, and he served them via welfare programmes<sup>7</sup> (Mian, n.d.). These role models and leaders were the pioneers who helped reform and establish social systems to be more inclusive of disadvantaged people.

In order to emphasise the Islamic importance in the aspect of both the Saudi political system and the Saudi culture, a discussion of the Islamic perspectives on individuals with disabilities in general, and how the Islamic

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<sup>6</sup> The first leader of the Muslims was the Prophet followed by Abu Bakr AsSiddeq, and then Umar bin Al Khattab.

<sup>7</sup> <http://www.saaaid.net/Minute/195.htm>

perspective influences Saudi initiatives in caring for individuals with special needs in particular, is needed since the study's cornerstone focuses on the establishment of an early intervention service for autistic individuals. Therefore, considering the Islamic content is essential due to the fact that the Holy Qur'an and the Sunnah serve as a basis for Muslims' concepts, attitudes and behaviour towards every aspect of their life, including the concept of disability. Miles (2002) reported that understanding people's cultures and their notion of disability is required in order to develop the appropriate services. Thus, the following paragraphs will firstly illuminate the Islamic perspective on individuals with special needs and their rights, and secondly focus on the various types of treatment.

## **2.4 The Islamic Perspective on the Disability Concept**

Having stated that the Qur'an and the Sunnah are the foundation for Muslim's behaviours and beliefs, a general notion of disability within these two sources will be discussed. Islam has given a great amount of attention to all groups of society; each of which has their own rights, including individuals with special needs. Bazna and Hatab (2005) conducted a study with the objective of examining Qur'an texts for understanding disability in an Islamic context based on examples of physical conditions, such as being blind, deaf, lame, mentally retarded and having leprosy. An example of such from the Qur'an (Chapter 48, Verse 17):

*“There is not upon the blind any guilt or upon the lame any guilt or upon the ill any guilt. And whoever obeys Allah and His messenger – He will admit him to gardens beneath which rivers flow: but whoever turns away- He will punish him with a painful punishment”.*

In addition, other general terms, such as weak, sick, orphaned and needy individuals, were also referenced. For example, the Qur'an (Chapter 76, Verse 8-9) states:

*“and they give food in spite of love for it to the needy, the orphan, and the captive, [saying] we feed you only for the countenance [i.e., approval] of Allah. We wish not from you reward or gratitude”.*

Bazna and Hatab (2005) concluded that the generic term 'disability' was not mentioned in the Qur'an; alternatively, the notion 'disadvantaged people' was being used to refer to those with special needs. In addition, the society's civil responsibility was illustrated in the Qur'an, stressing that the society is responsible for taking care of such individuals and is responsible for improving their condition. Disadvantaged situations (lack of some physical, economic or social characteristic) are believed to be a result of barriers produced by society. Social pressures are put upon individuals with special needs to access some of the social services that are made available. This notion is similar to how the UN Enable-World Programme of Action Concerning Disabled Persons defines handicap – as a disadvantage for a given individual<sup>8</sup>. Although the term “disadvantaged” could be seen as more holistic, the genre accommodates several disabilities and impairments.

The Sunnah also supports the notion of social responsibility towards individuals. A few examples of such are found in the following two hadiths. According to Prophetic tradition mentioned in Sahih Muslim, *“The similitude of believers in regard to mutual love, affection, fellow-feeling is that of one body; when any limb of it aches, the whole body aches, because of sleeplessness and fever”* (Volume 32, number 6258:). Another hadith narration from Sunan al Tirmidhi states *“the person is not one of us who is not merciful to our youth and respectful of our elder”*<sup>9</sup>.

Cooperation, solidarity, merciful and respectful are some examples of Islamic principles and manners that the stated hadiths have given to support the idea of the society's responsibilities towards each other, as indicated in the Qur'an.

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<sup>8</sup> <http://www.un.org/disabilities/default.asp?id=23>

<sup>9</sup> <http://hadith.al-islam.com> Arabic version 12/07/09

#### 2.4.1 Disadvantaged People's Rights and Obligations

The two previous paragraphs discussed the notion of disability and its existence in the Qur'an and hadith texts. In fact, the idea of individuals being in a disadvantaged situation was provided. The following paragraph illustrates some examples where both the Qur'an and the hadith exemplify their rights and the social duties towards them, along with some historical references in Islam.

Indeed, the rights of disadvantaged people are mentioned in the Qur'an's text on several occasions. For instance, their civil right in marriage and inheritance are clarified in the Qur'an:

*“and do not give the weak-minded your property, which Allah has made a mean of sustenance for you, but provide for them with it and clothe them and speak to them words of appropriate kindness”* (Chapter 4, Verse 5).

*“And test the orphans [in their abilities] until they reach marital age. Then if you perceive in them sound of judgment, release their property to them. And do not consume it excessively and quickly, [anticipating] that they will grow up. And whoever, [when acting as guardian], is self sufficient should refrain [from taking a fee]; and whoever is poor – let him take according to what is acceptable. And then when you release their property to them, bring witnesses upon them. And sufficient is Allah as accountant”* (Chapter 4, Verse 6).

Another Qur'an verse in the same chapter tells us *“and concerning the oppressed among children and that you maintain for orphans [their right] in justice”* (Chapter 4, Verse 127). Reading interpretation books of the Qur'an, “tafsir” such as Ibn Ashur (1973) and Tantawi (1928)<sup>10</sup>, is required in order to understand the deep meaning of these texts.

From the sources and texts from the Qur'an and the hadiths as mentioned above, the following statements can be deduced:

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<sup>10</sup> <http://www.altafsir.com/Tafasir.asp>

- First, “*weak-minded*” is a generic term that could comprise several groups, such as very young children, mentally retarded and mentally ill individuals, etc.
- Second, the texts lay down the idea of guardianship for disadvantaged individuals, such as the weak-minded or orphans.
- Third, this guardianship is subject to a sense of duty, fairness and kindness. In addition, guardianship ceases once the individual can be held accountable for their own decision making ability.
- Finally, there is a reminder from Allah that all wealth provided by Him is for the maintenance of the community as well as of individual members.<sup>11</sup>

Indeed, the previous texts, along with others that are mentioned in the Qur’an, have helped Muslim scholars and jurists to generate several legislations regarding disadvantaged individuals’ rights and society’s duties towards them.

#### 2.4.1.1 Marital Rights

Marriage is another example of disadvantaged individual civil rights. Recently there was a strong debate among Islamic scholars and physicians over the idea of whether mentally retarded individuals should be allowed to get married. For example, in the first conference held by Mental Retarded Society in 2002, under the supervision of Al Azhar University in Egypt, some scholars argued that it is acceptable and that it is part of their right to get married. This is because sex is an innate driver that should be met. They suggested that marriage will help in controlling any sexual behaviour that might be practiced or exhibited inappropriately by such individuals. However, marriage should be under certain conditions and with guardian supervision. On the other hand, some scholars see marriage more as a

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<sup>11</sup> <http://quran.alislam.com/Tafseer/>

responsibility than a sexual practice. Therefore, mentally weakened individuals are not capable of holding this responsibility even with the guardianship (Asharq Alawast, 2002)<sup>12</sup>. Such kinds of debate are still ongoing, with jurists have different interpretations and opinions. Miles (2002) stated that the debate among Muslim scholars and jurists regarding the mentally weakened individuals' civil rights have existed in Islamic history, centuries before it did in Europe.

#### 2.4.1.2 Right of Education and Social Status

Disadvantaged people have a right to be educated and their abilities should not be underestimated. This right is illustrated clearly in the Qur'an "*He [the Prophet] frowned and turned away because there came to him a blind man, But what would make you perceive, [O Muhammad], that perhaps he might be purified, or be reminded and the remembrance would benefit him?*" (Chapter 80, Verses 1-3). Allah rebuked His messenger, Muhammad, when he turned away a blind man asking the Prophet to teach him about Islam. This is because the Prophet was busy pursuing people of nobility to become Muslim. A deep analysis of the situation reveals several lessons that could be retrieved from the verse. These lessons are:

- Individuals have a right to be treated equally: everyone is equal in regards to importance, regardless of whether the person is disabled or not.
- Individuals have a right to be educated regardless of disability.
- Individuals have a right not to be underestimated because of his/her ability.
- Individuals have a right to be included within society and to have an effective, valuable role in it.
- Obligations are placed upon disabled individuals to seek out the proper resources for education (etc) and not to underestimate their own ability and societal role.

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<sup>12</sup> <http://www.aawsat.com>

As a result of Allah's reprimand, the Prophet was more welcoming to this blind man whenever he saw him. The Prophet even handed over the leadership of the city of Madinah, the second holy city in Saudi Arabia, twice to the blind man (Bazna and Hatab, 2005; Miles, 2002; Ibn ashur, 1973; Tantawi, 1928). Furthermore, the Sunnah supports the notion of equality that has been discussed earlier within the Qur'anic text and made it clear that there is no difference between people in terms of their physical appearance, their colour, and/or their nationality. They are all treated equally and differ only on the amount of faith they have. It is stated in the Qur'an "*Indeed the most noble of you in the sight of Allah is the most righteous of you*" (Chapter 49, Verse 13). This idea is also highlighted in the Prophetic hadith, mentioned in *Sahih Muslim*, in which the Prophet said: "*Verily Allah does not look to your bodies nor to your faces but He looks to your hearts*" (Volume 32, Number 6220).

#### 2.4.1.3 Rights of Protection

Another example of human rights toward disadvantaged individuals is the protection of honour. According to the Qur'an "*O you who believed, let not a people ridicule [another] people; perhaps they may be better than them; nor let women ridicule [another] women; perhaps they may be better than them. And do not insult one another and do not call each other by [offensive] nicknames*" (Chapter 49, Verse 11). The message to be learned from this Qur'anic verse is basic human rights such as respectfulness, applied toward both disabled and non-disabled individuals by avoiding over-generalising and underestimating others.

The Qur'an emphasises the notion of social responsibilities and duties in order to provide disadvantaged individuals with their basic needs, such as food, care and shelter, where the Qur'an, (Chapter 24, Verse 61) states: "*there is not upon the blind [any] constraints nor upon the lame constraints nor upon ill constraints nor upon yourselves when you eat from your [own] houses or the houses of your father or the houses of your mother or the*

*houses of your brothers or the houses of your sisters or the houses of your father's brothers or the houses of your father's sisters...".*

The previous examples have exemplified the existing notion of disability in the Qur'an and the Sunnah. The following sections will consider the Islamic perspective of disability rehabilitation, the Muslim attitude toward disability and the development of disability services in Islamic history.

#### **2.4.2 Treatment and Rehabilitation**

From the Islamic perspective, rehabilitation could be seen through two levels, preventive and remedial level. Having said that, the Qur'an and the Sunnah shape Muslims' perspectives and behaviours, as these two sources help to identify the several texts that been used by jurists to generate laws and regulations. These laws and regulations concentrate on prevention and treatment of disabilities. Prevention can be managed through medication or by changing one's lifestyle, whilst treatment for the disabilities can be medication, rehabilitation, or spiritual medication. The following subsections discuss further examples of treatment methods and provide some relevant text along with its meaning so that one can understand the basis on which the Islamic rules are generated.

#### **2.4.3 Changing the lifestyle**

Islam has warned individuals against anything that might affect him/her negatively. Harming one's body is prohibited because one's body is viewed to be a trust from Allah, as according to the Qur'an, "*And spend in the way of Allah and do not throw [yourselves] with your [own] hands into destruction*" (Chapter 2, Verse 195), 'destruction' in this verse indicates and includes a variety of human behaviours, such as being an alcohol or tobacco addict, due to the bad side effects that both have on the individual's health and his/her surroundings. For instance, addicts could be discussed within the context of acquiring a disability since there is scientific evidence of the side effects on the foetus' health during and after the pregnancy period.

Moreover, being an alcoholic might lead to the individual becoming mentally ill, which might then lead to him/her being classified as a disabled individual. Thus, giving such examples serves the purpose of clarifying the meaning of 'destruction' in the text. However, examples of individual's behaviours that might put him/her in a harmful situation are too many, and discussing them is beyond this scope of the study.

The notion of protecting someone from throwing themselves into harm's way is both an individual and a social responsibility. It is the individual's responsibility to evaluate his/her behaviour and to weigh the consequences of their actions, thus, changing one's lifestyle to a healthier one in order to prevent illness or disabilities is a must. Moreover, the previous verse has also inspired the idea of societies spending public money to offer education and health legislation and various facilities to serve its population.

An example of Saudi society implementing legislation to help prevent disabilities can be seen in the current actions of the Saudi government, making it compulsory for those who are going to get married to be medically cleared from some serious genetic inherited diseases before the marriage. This example shows how society has the ability to play an important role in protecting people.

#### **2.4.4 Medicinal Usage**

Using medicine for preventive and remedial purposes and by doing research to find more medicinal treatments or cures are some of the responsibilities of mankind based on a narration from *Sahih Bukhari*, narrated by Abu Huraira, the Prophet, who said, "*There is no disease that Allah has created, except that He also has created its treatment.*" (Volume 7, Chapter 71, Verse 582)<sup>13</sup>. The following hadith, taken from *Sunan Abu Dawud*, also clarified and insisted on the importance of medication, "*I came to the*

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<sup>13</sup><http://www.usc.edu/schools/college/crcc/engagement/resources/texts/muslim/hadith/bukhari/071.sbt.html>

*Prophet (peace-be-upon-him) and his Companions were sitting as if they had birds on their heads. I saluted and sat down. The desert Arabs then came from here and there. They asked: 'Apostle of Allah, should we make use of medical treatment?' He replied: 'Make use of medical treatment, for Allah has not made a disease without appointing a remedy for it, with the exception of one disease, namely old age'" (Volume 28, Number 3846). Thus, the majority of Muslim jurists agree on using medicine for both immunisation (preventative measure) and medication (treatment).*

#### **2.4.5 Immunisation: Physical and Spiritual**

A recent study of jurists' perspectives on the physical and spiritual treatment of disability in Islam found that disability is a condition that could be both prevented and treated (Ghaly, 2008). The Council of Islamic Fiqh concluded that mankind's responsibility is to use vaccination as well as medication. Indeed, the jurists provided a detailed explanation of medicine implications in different situations.<sup>14</sup>

Another perception of immunisation is in the form of spiritual immunisation via '*Tahsin*', which means 'fortification'. This method does not relate to any kind of physical medication; it is about spiritual treatment performed by using specific prayer supplications. According to Muslim belief, these supplications are an effective defence that helps in protecting an individual from being vulnerable to bad things that might happen to him/her. There are various texts from the Qur'an and the hadith that could be read on a daily basis which covers different aspects of an individual's life to protect him/her against dangers. These prayers should be performed when waking up, before sleeping, before eating, after eating, leaving home, returning home, etc. Therefore, Muslims perform a variety of daily supplications before and after doing any activity, with the faith that Allah will help and protect them.

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<sup>14</sup>Readers who are interested are referred to the following link for further details.  
<http://islamqa.com/en/ref/2148>.

In addition to the above mentioned tahsin (spiritual treatment), other types of treatment from a variety of sources could be implemented on many levels. According to the Qur'an (Chapter 17, Verse 82), "*and we send down the Qur'an that which is healing and mercy for the believer*", there is some controversy over its meaning. Some claim that the Qur'an is a healing for both physical and spiritual illnesses, whilst others believe that the Qur'an is a spiritual treatment that helps in easing fears, worries and stress that are symptomatic of mental discord and brings individuals closer to Allah and strengthens individuals' trust in Him (Al-Sharawi, 1998)<sup>15</sup>.

Therefore, one can conclude: first, rehabilitation from an Islamic perspective consists of both physical and spiritual medication whether within a preventive or medication level. Second, Muslims believe that depending on Allah along with taking a course of treatment should be applied to both rehabilitation levels. These two principles were generated from several sources in the hadith and the Qur'an. An example of such is found in the Qur'an verses:

"And when I am ill, it is He (Allah) who cures me" (Chapter 26, Verse 80) and "*Say "never will we be struck except by that which Allah has decreed for us; He is our protector." And upon Allah let the believers rely*" (Chapter 9, Verse 51).

#### **2.4.6 Application of the Islamic Perspective**

Overall, the Muslim attitude towards disability is a continuation of what has been discussed previously, since it is generated from their faith and their belief in Allah. In fact, there are general principles found within the basic principle of faith that frame the Muslim's attitude toward disability. These include:

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<sup>15</sup> <http://www.altafsir.com/Tafasir.asp> Arabic

- ✓ Believing in ‘qadar’ which is “the belief in preordination (fate or destiny), which supports the idea that what is meant to be, will be, and what is not meant to happen, can never occur” Hasnain et al., (2008). This was stated in the Qur’an (Chapter 9, Verse 51). Based upon this principle, disability could be regarded as an act of God and that it is part of individual’s ‘qadar’. Indeed, believing in ‘qadar’ is an extension of believing in Allah and His divine wisdom and plan.
- ✓ Believing in the concept of “reward and punishment”, both in this life and the hereafter, is a vital principle that insists on individuals being responsible for his/her behaviour, not only in their actions but also in the motives and intention behind the actions. Violating Allah’s laws has its own consequences not only in the life but later on at the Day of Judgment.

It is stated in the Qur’an that “*so whoever does an atom’s weight of good will see it, and whoever does an atom’s weight of evil will see it*” (Chapter 99, Verses 7-8). In fact, several other Qur’an and hadith narrations have demonstrated promises to both those who are in a disadvantaged situation and those who are taking care of them, with rewards in both life and the hereafter for their patience. Indeed, this promise usually motivates people into supporting disadvantaged people, whether those people are strangers or close relatives.

In spite of the fact that Muslims share almost the same beliefs and principles, parental attitude, understanding towards the concepts, and reactions towards their child’s disability, which might vary according to the individual’s level of faith, socioeconomic level, educational level, awareness of the child and the child’s appropriateness, there are other variables that coexist with the surrounding culture and can affect the parents’ behaviours and attitudes.

As discussed previously disability within the Saudi context has a moral or religious significance, where disabilities could be seen as a blessing, or as a curse. For example, disability could be described as an example of the need to be 'fatalistic' in the acceptance of difficulties in life; Islam requires submission to the will of Allah. Therefore, the presence of a disabled child is seen to be a test of faith. However, cultural perspectives might be mixed with religious values and can often lead to several courses of action, which may be falsely attributed to religious faith, such as attempting to explain the cause of the disability, and by looking for solutions.

For instance, parents who have a child with a disability may resort to their religion to explain the problem away. One explanation is when the parents of disabled children attribute the disability to themselves by considering the disability to be a punishment from Allah or God's bidding (Hasnain *et al.*, 2008) which should be obeyed. Some consider that a disability in the family is a curse from Allah for the parents and the family (Miles, 2002).

Envy (*Hasad or the evil eye*) is at the top of these explanations, as many people believe that having a disabled child is the result of envy. Although envy has its roots in Islam (the Qur'an and Sunnah), it seems that parents use such an argument, which would be accepted by the surrounding religious community. Based on this belief, parents tend to deal with disability within their cultural context. This includes using amulets (Hasnain *et al.*, 2008) and spiritual treatment.

Thus, when identifying and examining the parental role of an autistic child one must consider the attitudes and perspective of their child's disability within the context of their culture. This is the main focus of this study, and therefore, parental attitudes and behaviours will be covered in further detail through interviews and questionnaires within Chapter five.

Even with such role models and leaders throughout history, and a compassionate set of ideals as a basis of their religion, it is hard to imagine

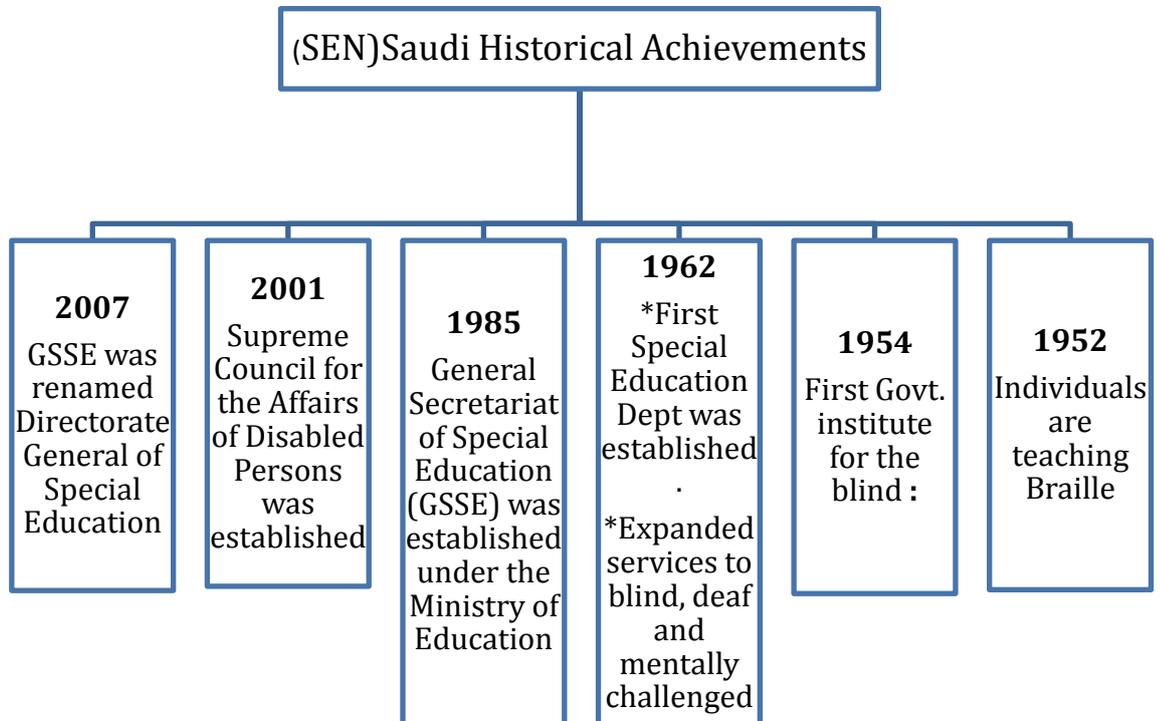
the current position of disadvantaged individuals in Saudi Arabia and the limited services that are currently being offered. This is due to the fact that programs and services are still in the development process, because many of the Islamic countries have undergone, and are still going through, many changes especially in the areas of politics and economics. As a result, many of these adjustments have tremendously affected every aspect of people's lives, which includes caring for needy individuals.

## **2.5 Special Needs within the Saudi Context**

To understand the current situation, a brief exploration on the Saudi efforts in caring about individuals with special needs follows. Islamic philosophies along with the international convention, which is based on the rights of disabled individuals, will be considered.

In 1952, through individual efforts, caring about individuals with special needs began by teaching blind people to read using Braille (Alsunbl et al., 2004). Today, the special needs genre, which has become a focus for the Saudi government, has broadened incorporating a variety of disabilities with different degrees of severity. The government recognizes special needs individuals as a valuable part of society. In doing so, the government recognizes the need and potential for these individuals, who given the right support and guidance can become productive members of society by taking into account their own abilities, their duties, and their rights. Indeed, each government sector has offered special needs individuals support and help based on the sector's mission and vision; however, some sectors' involvement has played a crucial role in establishing and improving services, more so than other sectors. This discussion will focus on the involvement of each sector (education, social affairs, health, media, and transportation) in such services, starting from the most to the least contributory efforts. Finally, the development of the autism services will be demonstrated.

Figure 5 Special Education Needs Development in Saudi  
Source: compiled by author



### 2.5.1 Education services

The Saudi government has established educational services for individuals with SENs (Special Education Needs) see figure 5. In 1954, the first government institute for blind people opened under the control of the Ministry of Education in Riyadh. This was followed by the establishment of a special education department in 1962 which was considered to be a cornerstone for SEN services in Saudi Arabia. As the Department of Special Education expanded educational services to include blind, deaf and mentally retarded individuals, institutes were established all over the country to accommodate their needs; however, the objective of the services was not clear. Since then, SEN understanding has rapidly increased (Alsunbal et al., 2004).

In 1985, the General Secretariat of Special Education (GSSE) was established as a division of the Ministry of Education. The GSSE charter is composed of (102) issues addressing special education. The GSSE policy is based on Islamic rules that education should be for all. The following are examples of policies and the issues being addressed that are relevant to this study. For example, one such policy is that the responsibility to provide education falls upon the government (Issue 10). Enshrined within the policy is the government's responsibility towards respecting the human rights of children with SENs and providing basic human needs (Issue 20). Caring about children's spiritual, psychological and social growth is also regarded as being essential (Issue 53). The policy includes identifying individual differences between children as also being important, as this helps the children to develop their abilities and talents (Issue 54). The policy shows that SEN provision is a completion of ordinary education and includes diverse provisions (Issue 93).<sup>16</sup>

The GSSE's role is the general overall planning and supervision of SEN provision for children with SEN in the Kingdom. This includes identifying and assessing children, planning suitable services, and providing educational services in the least restrictive environment for those children. SEN provision takes place in either special school, in special classes within the mainstream school, or in ordinary classes with supervision from a SEN teacher, depending on a child's needs.<sup>17</sup>

The entire range of education resources (such as textbooks, visual and hearing aids, teaching aids) are provided free of charge for the students. In addition to the educational services, each student is given a monthly allowance depending on his education stage. Daily transportation is also available for the students. Moreover, teachers within special educational programs are given the sum of an extra 20% to 30% of their salary,

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<sup>16</sup> [http://www.se.gov.sa/rules/se\\_rules/index.htm](http://www.se.gov.sa/rules/se_rules/index.htm)

<sup>17</sup> (<http://www.se.gov.sa/English/index.htm>)

depending on whether they are special education teachers or subject matter teachers. Thus, this kind of privilege serves the purpose of:

- ❖ Enhancing a teacher's motivation towards working with individuals with special needs.
- ❖ Attracting more teachers to specialise within this field.
- ❖ Rewarding their efforts and patience, as working within the disability domain is not an easy task.<sup>18</sup>

Building on this, the GSSE has set targets for SEN provision. These targets are:

1. early identification of people with SEN
2. To locate the closest resources that can offer education services based on the individual's geographical requirements.
3. To offer the educational provision that the children need.
4. To educate the parents about their child's strengths and weaknesses.
5. To build a good relationship between the parents and the child's teacher.
6. To prepare both mainstream schools and special schools to accommodate children with SENs and to meet their needs.
7. To update and review these targets based on the observations of the policy implementation made by the teachers, head teachers, and the school Authority.<sup>19</sup> Summary Statistics 2009/2010

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<sup>18</sup> (<http://www.se.gov.sa/English/index.htm>)

<sup>19</sup> <http://www.se.gov.sa/AboutUs.aspx>

Table 3 Special Education Statistic (2006/2007) in Saudi Arabia  
 Source: DGSE<sup>20</sup>

Type of Disability	# of Institutions and Programs	# of Students
1.Hearing Disabilities	420	8684
a) deaf	300	4913
b) hard of hearing	120	3771
2.Visual Disabilities	218	3676
a) blind	216	1606
b)low vision	2	2070
3.Mental Retardation	805	15856
4.Learning Disabilities	1237	11919
5.Gifted and Talented	314	17234
6. Autistic	65	515
7.Multi-Disabled	62	504
8.Physical Disability	1	1642
9.More than type	8	1059
Total	3130	61089

<sup>20</sup> <http://www.se.gov.sa/English/Statistics.htm>

Table 4 Statistics for the year 2008/2009  
Source<sup>21</sup>

	Gender	schools	classes	Student	Staff
SEN	Male	529	3,802	17,489	4,827
	Female	144	776	5,345	1,831
	Total	673	4,578	22,834	6,658

Table 5 Statistics for the year 2009/2010  
Source<sup>22</sup>

	Gender	schools	classes	Student	Staff
SEN	Male	1.064	3,628	17,393	5,383
	Female	487	1.540	8,932	2.419
	Total	1.551	5,168	26.325	7.802

Table 6 Statistics for the year 2010/2011  
Source<sup>23</sup>

	Gender	schools	classes	Student	Staff
SEN	Male	1.066	3,778	17,718	5,657
	Female	528	1.453	9.420	2,202
	Total	1.594	5.231	27,138	7,859

Throughout the last two decades, the GSSE has demonstrated a holistic leap in the qualitative and quantitative development of the necessary plans and programs that serve the blind, deaf and mentally retarded individuals, but also by putting forth continuous efforts to develop and solidify an education

<sup>21</sup> <http://portal.moe.gov.sa/Pages/stat30-31.aspx>

<sup>22</sup> <http://portal.moe.gov.sa/Pages/stat30-31.aspx>

<sup>23</sup> <http://portal.moe.gov.sa/Pages/stat30-31.aspx>

provision to include an array of disabilities. These categories include: hearing impairment, visual impairment, learning difficulties, emotionally and behavioural disorders, autism, communication disorders, physical disability, and those with multiple disorders. Moreover, the numbers of institutes and programmes that accommodate individuals with SENs have increased from having only 66 institutes and programmes in 1996 to having 1.594 institutes in 2011 see tables (3-4-5-6).

Along with this expansion in the quantity and quality of special educational services, in 2007 the GSSE had its name changed to the Directorate General of Special Education (DGSE). This resulted in the preparation of: first, increasing the number of departments from only three to eleven management, technical and administrative departments, namely.

- ✓ Management of Visual Disability.
- ✓ Department of Auditory Impairment.
- ✓ Department of Intellectual Education
- ✓ Management of Learning Difficulties.
- ✓ Department of Autism and Multiple Disabilities.
- ✓ Executive Management.
- ✓ Management and Development Studies.
- ✓ Housing Department Procedure.
- ✓ Management of Computer and Technology Education.
- ✓ Management of Public Relations and Educational Outreach.
- ✓ Department of Management.

Second is the preparation to develop a new educational proposal with the aim of improving DGSE services. The new strategy is based on the following areas :

- Activate the mainstream school role towards accommodating more children with special needs.
- Expand institutes with a special education role so they will become information centres and training institutes.
- Adapt modern technology to serve individuals with special needs.

- Develop a special educational curriculum and programmes.
- Study the existing regulations in order to develop and prepare for new regulations and future programs.
- Activate the scientific research role in the field of special education.
- Cooperate and coordinate with relevant agencies within and outside of the Kingdom of Saudi Arabia .
- Care about human care development (Almoosa, 1999).

In spite of the fact that there is a rapid growth in educational services and programmes that are being provided for individuals with special needs, many programmes and services are currently being developed by the DGSE, so therefore a lot more programs are expected.

### **2.5.2 Social Affairs Services**

The Social Affairs Services integrate and deal with treatments, rehabilitations, and social services for all categories of disabilities, whether mental, physical or mobility disabilities. These services vary depending on the needs assessment (accommodation, rehabilitation and occupational therapy) and depending on the disability type and its degree of severity. An annual allowance is also given for those who cannot be accommodated, or those cared for by their families. Public administration for the care and rehabilitation of people with disabilities falls under the responsibility of the department that is offering such services.

The Public Welfare Agency comes under the Ministry of Social Affairs. Its role is the general overall planning, supervision and follow-up to provide rehabilitation services for individual with disabilities. Thus, rehabilitation, as defined by the Supreme Council for the Affairs of Disabled Persons, is “a coordinated process of medical, social, psychological, educational, and professional services recruitment to assist disabled individuals to achieve

the maximum possible degree of functional efficiency, as well as individual independence, to be as productive a member of society as possible” .

Public administration for the care and rehabilitation of persons with a disability is coordinated in three subdivisions (social, vocational and civil rehabilitation) of the overall care and treatment of the individual so that the objectives can be defined for a plan of action to be implemented in order to achieve the desired goal. These objectives are designed to:

- ❖ Propose rehabilitation’s plans programs and activities in coordination with the relevant departments.
- ❖ Ensure the provision and evaluation of services for individual with disabilities.
- ❖ Develop rehabilitation bases and procedures.
- ❖ Study the families of individuals with disabilities’ financial grants and approval according to the rules and regulations.
- ❖ Coordinate with the health agencies to ensure that full health care is provided.
- ❖ Coordinate with the Ministry of Civil Service and the employment offices in order to find and create job opportunities that fit such individuals.

The involvement of the private sector in providing day care rehabilitation services was established in 1990 as a new route to providing such services. Thus, this new route encourages individuals and institutions to contribute to charitable works in the field of disability. Consequently, sixteen centres were granted licences and the permission to establish private day care under the supervision of the Social Affairs Ministry.<sup>24</sup>

### 2.5.3 Health Services

The State shall guarantee the rights of individuals with disabilities by providing health services and working towards improving healthcare by

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<sup>24</sup> <http://mosa.gov.sa/portal/modules/smartsection/item.php?itemid=11>

taking the necessary steps to achieve this. The following provides a general overview of the provided services via the health sector for individuals with a disability.

- ❖ Provide preventive and curative services such as the early detection of diseases, immunizations and a whole set of medication and medical equipment that an individual might need.
- ❖ Register newborn children who are vulnerable to disability, follow up their cases and report to the concerned authorities.
- ❖ Train health workers annually and equip them with the newest developments and growth within the field of healthcare.
- ❖ Train families on how to deal with and accommodate their children who are individual with disabilities.

Thus, the previous discussion illustrates the roles of the three main governmental sectors that are predominantly involved in providing the basic and essential services of health, education and rehabilitation. Other governmental sectors are responsible for offering a set of complementary services such as:

- ✓ Create a safe means of public transportation and reduce its cost.
- ✓ Activate the media role in raising people's awareness about disability, its causes, and the rights of disabled individuals.
- ✓ Create opportunities for individuals with disabilities to use sports facilities and to participate in internal and external sport events.

As a continuation of the governmental efforts to facilitate, unify and to improve both the quantity and the quality of services provided for individual with special needs, in 2001, a Supreme Council for the Affairs of Disabled Persons was established and issued with the Royal Decree No. (M / 37) and was approved by the Council of Ministers Decision No. (224). The establishment of such a council reflects the governmental concerns to help and support individuals with special needs. The council's system consists of sixteen issues that illustrate several definitions, guidelines and principles related to the services and facilities that should be provided for individuals with special needs.

The Supreme Council consists of a Chairman of the Council of Ministers, a position that is royally appointed along with representatives for the Minister of Labour and Social Affairs, the Ministry of Education, the Ministry of Health, the Ministry of Finance, the Ministry of Higher Education, Municipality and Rural Affairs, Secretary General of the Council, two disabled individuals, two businessmen who are interested in the affairs of the disabled, and two disability specialists who are appointed by the President of the Council of Ministers based on the nomination of the President of the Supreme Council for a period of four years, that is subject to renewal. The Supreme Council reports annually to the Prime Minister, consisting of the current situation of persons with disabilities, the services provided to them, and difficulties that they might face in offering such services. Moreover, the existence of this council helps towards the unified governmental agencies efforts in providing services for needy people.<sup>25</sup>

The role of this council is to:

- ✓ Issue system implementation regulations and decisions.
- ✓ Monitor regulations and decisions implementation.
- ✓ Coordinate between the various governmental and private agencies in respect to services provided to persons with disabilities.
- ✓ Encourage scientific research within the disability area.
- ✓ Examine the annual reports issued by the government agencies for achievements and progress in prevention and rehabilitation, and to take any necessary action based upon them.
- ✓ Issue of the work of the Fund for the Welfare of Persons with Disabilities.
- ✓ Declare the council's opinion on international agreements regarding disabilities and on the country's participation within

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<sup>25</sup>(<http://www.se.gov.sa/di-act/index.htm>)

organizations and regional bodies and international affairs related to the care of persons with disabilities.

Recently, in 2008, the Saudi government established the Committee on the Rights of Persons with Disabilities. This commitment opened the door for information, knowledge and experience exchanging within this field. As part of the global awareness movement, the Saudi government have highlighted concerns and awareness of disability issues and the importance of having up-to-date information.<sup>26</sup>

## 2.6 Autism Services

As previously mentioned, despite historical role models some areas of the special needs genre are still currently being developed. Caring about individuals with autism started through individual efforts in 1993. The Al-Faisalya Women Welfare Society in Jeddah was the first to establish a small class that consisted of four children with autism and to undertake the training of five teachers to manage the class. The training was supervised by Dr Samira Alsaad, who is herself a mother of a child with autism and a specialist within the autism field. This class was the first of its kind to offer educational intervention services for individuals with autism, not only in the Kingdom of Saudi Arabia, but also in the Gulf area. This class developed to become one of the pioneering private centres for individuals with autism in Jeddah.<sup>27</sup> After that, the government started to facilitate and establish government sponsored programmes and educational services in 1998; the first of which were educational programmes attached to special educational institutes in Saudi's main cities, Riyadh, Jeddah, and Dammam.

Following this, the media campaign was launched in 1999 to raise awareness of autistic children and their parents requesting public services to

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<sup>26</sup> (<http://www.se.gov.sa/convoptprot/index.htm>)

<sup>27</sup> ([http://www.jacenter.org/ara/mrakz\\_w\\_msharea/mrkz\\_jdah\\_lltwhd](http://www.jacenter.org/ara/mrakz_w_msharea/mrkz_jdah_lltwhd))

accommodate their children's needs. In response to the media campaign on Autism:

- ✓ Another private centre was established in the capital, Riyadh, in 1999.
- ✓ The Council of Ministers issued an order for a study to be undertaken by the Ministry of Health to investigate autism. The study results were published in 2005, and the results showed that there were 120,000 autism cases in Saudi Arabia (Al-jarallah, 2005).<sup>28</sup>
- ✓ The Council of Ministers formed a committee to identify the required facilities for such a category of people under the supervision of the Ministry of Social Affairs (Alghanim, 2005).

Another important step towards establishing services for autistic individuals was the launching of the National Project for Children with Autism by the Council of Ministers in 2003. The aims of the project were:

- ❖ Providing diagnostic and intervention services
- ❖ Establishing three governmental centres within Saudi's main cities (Riyadh, Jeddah, Dammam).
- ❖ Establishing the Saudi Autistic Society
- ❖ Implementing academic courses on autism within the college and universities in order to prepare qualified teachers within the autism field (The Saudi Autistic Society, 2003).<sup>29</sup>

In 2004, the first governmental autism centre was established in Jeddah, and the first government centre for both diagnostic and early intervention was opened in Jeddah in 2007. More recently, the First Scientific Forum of Autism Centres in the Arab World was held, supported by the Arab Gulf

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<sup>28</sup><http://portal.kacst.edu.sa/Ar/aboutkacst/Headlines/Lists/List/DispForm1.aspx?ID=1968>

<sup>29</sup>[http://saudiautism.com/index.php?option=com\\_content&task=view&id=1&Itemid=2](http://saudiautism.com/index.php?option=com_content&task=view&id=1&Itemid=2)

Program for United Nations Development Organizations (AGFUND) in November 2008 (Autism Forum, 2008).

The Saudi government is trying to find ways to accommodate the growing number of autistic children and to provide them with the services that they need. Despite the fact that there are no statistics to show the exact number of individuals with autism, an estimation of the prevalence of autism in Saudi Arabia could be anticipated and calculated based on the autism incidence internationally. Two recognized different rates have been reported in the literature as follows: 6 in 1000 children (Baird et al., 2006); and 10 in 1000 (the Medical Research Council, 2001). Accordingly, and based on the Saudi population which is 27,136,977 million people, between 162,000 and 270,000 is an estimation of the incidence of autism in the country. Recent statistics published via the Ministry of Education shows that there are 51 governmental programmes, consisting of 145 classes and 188 teachers across different parts of the Kingdom to potentially accommodate 488 students. There are also private centres in which educational services are provided; however, there are no statistics to show the exact number of centres that are available or the number of students that are being accommodated (MoE, 2011).<sup>30</sup>

Previous developments show that there is positive evidence of the growing movement and development towards establishing general special needs services, and particularly autism services, in Saudi in which every aspect and principle of the services will be provided for individuals. The discussion has clarified that both individual and governmental efforts are paralleled to reflect the Islamic philosophy of community responsibility towards individuals with a disability.

Even though, there were modest attempts for early individual efforts in special needs services that initiated the government's involvement in these

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<sup>30</sup> <http://www.se.gov.sa/database/index.htm>

area. As previously illustrated, however, the numbers of individuals with autism accommodated are minimal compared to the existing number of individuals with autism that was published by in the 2005 autism study. Thus, one can anticipate that there are barriers, and this will lead the discussion towards exploring the challenges and obstacles that are facing the special needs services in Saudi Arabia.

## 2.7 Obstacles and Challenges Facing Special Needs Services in Saudi

Despite the fact that there is both individual and governmental willingness and efforts to provide and establish special need services, obstacles and challenges coexist when taking into consideration that the development of autism services in Saudi is still in its infancy stage. One issue is that autism was first recognised in 1993 even though other special need services have been established since 1952. Another issue that needs to be considered when examining such obstacles is that Saudi Arabia is a developing country that is seventy-seven years old, which unified in 1932. The following paragraph will exemplify and discuss examples of obstacles faced by special needs services and particularly autism services. Exemplifying these obstacles serves the purpose of providing positive criticisms. These criticisms might lead to both professionals and policy makers considering these barriers when devising future legislation with the aim of improving and modifying special need services.

Some of the following issues were discussed on several occasions and within different contexts, either at conferences and forums or in the media. An example of this is Al-haider (2006) in an Al Riyadh newspaper, who discussed some issues based on parents' complaints regarding the shortages of services that are being provided for individuals with autism and their families. Alsunbal (2004) discussed and raised some of these problems on his book. Every professional who is working closely within the field of special needs especially in Saudi Arabia needs to be aware of the potential barriers. However, the efforts to overcome and face these barriers are

modest and slow-moving. Here are some of the most recognisable problematic issues that confront special needs services in Saudi Arabia. However, other problems might also coexist.

- ✓ Lack of gathering and using accurate statistics on the quantity of disabled individuals, including those with autism.
- ✓ Shortages of expertise and qualified people who could develop effective services and could work efficiently with an individual with a disability.
- ✓ Limited programmes for raising people's awareness about disability, its causes and ways of preventing or adapting it.
- ✓ Modest services evaluation procedures as concern moves toward initiating services rather than evaluating them.
- ✓ Lack of local research within the disability field.
- ✓ Lack of early intervention programmes that cater for the 3-6 year old age group.
- ✓ Lack of an organised training and counselling program that offers education and support for families of individuals with a disability.
- ✓ Lack of recreational leisure activities and summer clubs for individuals with a disability.
- ✓ Limited academic tracks that offer special needs courses within Saudi colleges and universities.
- ✓ Absence of home visit programmes for social and health issues.
- ✓ Society has a mixture of attitudes between kindness and mercifulness as motivated by the Islamic philosophy, and discrimination and marginalisation driven by cultural issues towards individuals with a disability.
- ✓ Although resources are provided by the government to address the needs of individuals with autism, no evidence exists regarding the effectiveness with which these resources are being deployed.

## **2.8 Chapter Summary**

To summarise, this chapter aimed to provide an in-depth preview of the most influential factors that affect the development of special need services

(both general and autism services) particularly in Saudi where this study will be conducted. The main focus of this study is to develop a parental training programme that can lead to an early intervention home-based programme for individuals with autism. The highlight of the study's objectives is developing and providing services that generate from people's needs, along with the idea of considering their cultural context. Therefore, examining the Saudi background is essential at this stage, as this understanding will help in identifying the parents' needs within their context. Moreover, this understanding will help in identifying the best way to develop and to provide such a parental training package, being mindful of potential obstacles or barriers that might arise in developing and in offering such programmes, and in suggesting ways of dealing with them.

Following are the main ideas that have been covered within this chapter. These include:

- ❖ Basic and general information about the overall demographics and economic growth (government expenditures).
- ❖ Saudi systems of government (governmental sectors and Islamic law).
- ❖ Islamic perspective on disability.
- ❖ Development of special needs services in Saudi Arabia.
- ❖ Autism and available services.
- ❖ Challenges and obstacles confronting special needs services in Saudi Arabia.

General information about the demographics and economic status in Saudi Arabia was provided and discussed along with the Saudi government system and its influence by the Islamic Shariah Law. Afterwards, a detailed explanation of Islam and its two sources of jurisprudence have been discussed linking the Islamic perspective on disability (starting from the notion of a disability and its existence) to that within the Qur'an and the hadith narrations. A comparative discussion of the definition of disabled/disadvantaged individuals was presented, highlighting further issues, such as the rights of disadvantaged individuals and social

responsibilities. Indeed, an inclusive generic meaning to include disadvantaged individuals rather than just using the literal meaning of disability has been identified in Islamic texts as well as the individuals' rights, and social responsibilities were discussed within the Islamic context. In addition, the Islamic perspective on disability was exemplified and linked to Saudi government efforts to develop and provide services for individuals with a disability. This was illustrated by providing a timeline towards developing and providing such services and the roles of each governmental sector to do so. Finally, obstacles and confrontations facing special needs services and their development and providence were discussed in order to give the reader a clear picture and full insight in which this study will be conducted.

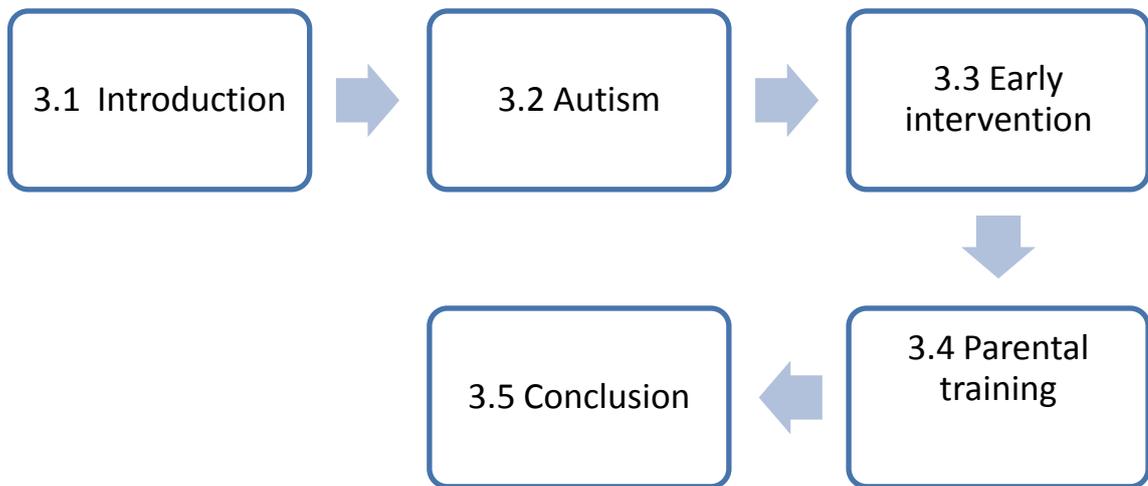
## **Chapter 3: Literature Review**

### **3.1 Introduction**

An in-depth look into the Saudi cultural context was given as well as background information highlighting historical aspects about special need services in Saudi in Chapter two. However, this chapter considers the relevant academic and professional literature in relation to three major areas associated with the establishment of a parental training programme in order to develop an early intervention home-based programme.

- ✓ The first section of the review concentrates upon the current understanding of autism spectrum disorders. Here, the chapter explores theories on autism, characteristics of autism and educational approaches.
  
- ✓ The second section of this review explores early intervention programmes for children with autism and their parents.
  
- ✓ The last section of the chapter focuses on a wide variety of literature in parental training programmes in order to establish an understanding of how these programmes have currently been provided.

Figure 6 structure of literature review



### **3.2 Autism**

Although developing a parental training course that leads to an early intervention home-based programme seems to be this study's major focus, providing general overview information about autism epistemology at this early stage within the study literature review will serve as the basis of the information for two reasons. Firstly, autism is the current study's cornerstone. Secondly, discussing a parental training course and early intervention approaches within the context of the current autism understanding is essential. Therefore, the aim of the first section is to examine autism and its current knowledge. Thus, the discussion will start with autism's history, definition and prevalence, followed by autism's nature, diagnosis, theories and ending with available interventions approaches.

#### **3.2.1 History of Autism**

Despite the fact that the early 40s saw the first emergence of the notion of autism as a separate condition, autism was already present. However, autistic individuals would be classified as mentally retarded, emotionally disturbed or schizophrenic. Indeed, autism recognition associated with two scholastic figures that first identified and defined autism as a unique

condition that differed from previously mentioned conditions. Hans Asperger, a paediatrician, and Leo Kanner, a child psychiatrist, described coincidentally and independently the autism condition through their work with their patients. In 1938, Hans Asperger provided a lecture in Vienna University Hospital to describe in German 'autistic psycho-paths' based on observations obtained from his case studies (Lyons and Fitzgerald, 2007). Asperger described four children with 'autistic psychopath'. His description of the condition's characteristics had highlighted the following symptoms: lack of empathy, limited ability to establish friendships, one-sided conversation, intense absorption in a special interest, and clumsy movements. Asperger's patients all had speech; therefore, Asperger Syndrome is often used to label individuals with autism that have the ability of speech (Frith, 1991).

In 1943, Kanner's work was first published in the English language where he provided an insightful explanation within the clinical context of 'infantile autism' as named by Kanner at that time. His description of the condition's characteristics had highlighted the following symptoms: extreme anti-social tendencies with a failure to relate to other people, failure to develop social awareness, objects orientation rather than people, resistance to change, obsessive, routine focused and failure to use language functionally, echolalia and good cognitive and intellectual capability. Kanner assumed that the condition was caused as a result of an innate inability. Moreover, he viewed autism as a result of a parenting style that lacked emotional warmth which led the child to withdrawal from unpleasant social contexts to his/her internal world (Kanner, 1968). Asperger's works were also in German; indeed, it was not before 1981, when Lorna Wing described Asperger's work in English, which was followed by Uta Frith's translation of Asperger's doctoral thesis in English, that Asperger's work had received the much due in the English autism literature.

Following the pioneers' establishment and efforts to define autism as a separate condition, many scientists showed their interest in autism, for

instance, Bettelheim, Wing, Rimland, Lovass, and Schopler, etc. Indeed, discussing their efforts in detail is beyond the scope of current study. However, it is relatively important to acknowledge such efforts in enriching autism epistemology. Therefore, some of these efforts are highlighted within the following paragraphs in line with the current study objectives when needed.

### **3.2.2 Autism Definition and Nature**

Autism is an invisible lifelong neurological and developmental disorder that affects an individual's social, communicative and normal imaginative growth, accompanied by stereotypical patterns of behaviour and interest. Although autism might be present from birth, its symptoms do not appear until a later stage of the child's development (Landa, 2007). Indeed, this could be linked to the notion that autism is a social deficiency. Since the time in which autism was recognized in the 1940s, which is over 60 years ago, abnormalities in social development, 'social game', is still recognised as a hallmark of autism (Volkmar and David, 2003; Marris, 1999). Wing (1988) built upon the first identification of autism suggested by Kanner in 1943, by describing it as a spectrum of disorders in which there are both commonalities and significant differences.

Thus, in order to be diagnosed with autism, at least two of the following three criteria must be identified in the child or adult: (1) a limited capacity in the understanding and use of non-verbal and verbal communication; (2) a limited capacity to understand social conventions and appropriate form of interactions; and (3) difficulties in thinking and acting flexibly. This can be summarised as the triad of impairments, as suggested by Wing, which may occur at different severity levels. Indeed, the differences in the level of severity of autism amongst the individuals lead to the use of the term "spectrum" (Tissot and Evans, 2006). Within this spectrum, five sub-groups have been identified based on specific behavioural features. These are Asperger's Syndrome; classic autism; disintegrative childhood disorders;

Rett's disorder; and pervasive developmental disorder not otherwise specified (Jones, 2002).

### **3.2.3 Theories and Causes**

Biological and psychological theories provided several clarifications and justifications in an attempt to understand autism's nature and its causes. Yet, the causes of autism could be seen as controversial as there is no clear-cut assumption or clear notion to justify the causes of autism. Some of the theories are discussed in order to understand what factors are attributed to the possible causes of autism.

#### **3.2.3.1 Biological factors**

Since the discovery of autism, both Asperger and Kanner had suggested a hereditary causal of autism. However, results obtained from studies conducted on twins and families failed to identify a single gene that could be contributed to autism development. The current medical view proposes a biological basis for autism that stems from the idea that several genes could be responsible for the damage in the brain which might sequentially lead to autism manifestation (Newschaffer et al., 2007; Marris, 1999; Baron-Cohen, 1993). Indeed, at the biological level much of the current studies remain speculative and more research is needed.

Along with the biological and hereditary causes of autism, the possibility of environmental causes, including diet, preservatives in vaccines, pollutants and birth trauma, are also thought to play a role. However, no empirical support for such a hypothesis has yet to be established which would enable a link to be drawn between any of these factors and autism manifestation (Baron-Cohen, 1993).

Greenspan (2006) suggested a multiple pathway model as a more flexible and comprehensive approach to understand the underlying causes of autism. Such a framework acknowledges that autism is a result of an interacting of

both genetic and environmental factors. For example, the child's biological predisposition might make him or her more vulnerable to developing autism when confronted with the environmental stimulus. This flexible approach would help in developing a broader understanding of all the surrounding causes in dealing with the complexity of autism instead of looking for one single cause.

#### 3.2.3.2 Psychological factors

While medical investigation proposes a biological base approach for autism, the psychological models proposes two approaches: the explanatory and the influential approaches. For example, the explanatory approach's main concern is trying to explain the disorders. The cognitive theories exemplify such an explanatory approach by attempting to identify the link between brain function and behaviour in autism. Three psychological models have been documented in the literature that has provided assumptions to explain cognitive dysfunction associated with autism. These are the 'executive function' model, the 'weak central coherence' and the 'theory-of-mind' hypotheses.

#### 3.2.3.3 Cognitive approaches

In contrast, the influential approach scientists' main concern is developing intervention approaches by utilizing various psychological theories and concepts into practice. The following intervention approaches are a good example of such efforts: the Applied Behavioural Analysis (ABA), Lovass (Smith and Eikeseth 2010), and the Developmental, Individual-differences Relationship-Based model (DIR) (Wieder and Greenspan, 2003). Therefore, the following discussion will examine the cognitive theories efforts in explaining the underlying causes of autism, whereas the efforts in providing the intervention implications based on the psychological theories will be covered in a separate section later on within this chapter.

The '*executive function*' theory assumes that autism is due to a deficit in executive functioning skills. These skills include problem solving, flexibly shifting attention, planning, and controlling oneself (Marris, 1999; Hill, 2004; Rajendran et al., 2007). However, criticisms over this explanation have been documented in the literature. Rajendran and Mitchell (2007) and Volkmar (2003) argued that the 'executive function' theory is limited in terms of providing a clear link between executive functioning skills and the social difficulty in autism, as its assumption might explain some of the autism feature. Furthermore, the executive deficits are not unique to autism and could be identified in other disorders.

The '*weak central coherence*' theory is another theory that attempts to explain autism causes within the context of cognitive deficiency. This theory suggests that an individual develops autism when s/he lacks the capacity to integrate information globally; a detailed-focused is the alternative which would lead to a deficit in attention and a depreciation of understanding in social meaning (Mottron et al., 2006; Frith, 2003; Happé and Frith, 2006). Indeed, the notion of central coherence has been criticised due to the existence of different understandings of this notion, along with limited research to support interpretations of the theory (Rajendran et al., 2007).

The '*theory-of-mind*' predicts that autism is a result of individuals with autism's failure to attribute the mental and the emotional state of oneself and others (Baron-Cohen, 2004: p.292; Baron-Cohen and Belmonte, 2005; Lockl and Schneider, 2007). Regardless of the fact that this hypothesis might provide an explanation to some features of cognitive delay that might be exhibited by a number of individuals with autism, the theory has been challenged, because not all individuals with autism fail to establish empathy and understanding of oneself and others (Bowler, 1992).

Thus, the previously presented psychological theories have tried to examine and to explain some of the autism underlying causes. Despite the similarities

to biological theories, none of them yet establish a clear and fully integrated understanding to explain autism characteristics. Debates over the causes of this mysterious and complex disorder still exist as there is no one clear-cut answer that is available, and searching for particular causes do not fit with the nature of multi-faceted autism (Rajendran et al., 2007).

### **3.2.4 Diagnosis and prevalence**

Over the last three decades, the recognition and understanding of the nature of autism and its resultant problems in social, communicative and imaginative skills has increased significantly. Therefore, examining diagnostic criteria in relation to the increased incidence of autism will be the focus of the following discussion.

The current approach to diagnosing autism is on an observational basis as there are no biological tests that exist to diagnose autism (Wing and Potter, 2002; Hill, 2004: p.722; Newschaffer et al., 2007). Alternatively, autism identified by using reliable scales consists of a range of behavioural criteria that need to be considered in order for a child to be diagnosed with autism. These include restrictions in social interaction, communication and imagination which are known as the triad characteristics of autism. Matson and Kozlowski (2011) argue that changing and developing the diagnostic criteria for autism is one of the central core factors for the increase of the incidence in autism.

Indeed, several diagnostic criteria have been suggested to identify autism within the literature. Yet, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and the International Classification of Disease, Tenth Edition (ICD-10) are the two most commonly used diagnostic criteria (Marris, 1999; Tissot, 2003; Matson and Kozlowski, 2011). Each of them provides a comprehensive list of criteria including symptoms for diagnosis and age of onset that has provided a structured framework for the use of clinicians to be able to assess and diagnose autism. Both tools have almost similar criteria, which are mostly based on the triad

of impairment in autism. Thus, the similarities between the two classifications have led to an almost worldwide diagnosis consistency (Matson & Kozlowski, 2011; Tissot, 2003). Based on the diagnostic criterion, several assessments or screening tools to diagnose autism were developed, for instance, Autism Diagnostic Interview-revised (ADI-R) (Lord et al., 1994) and Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). Such tools serve not only the aim of diagnosing the child, but also assessing him/her so that treatment or educational intervention would be suggested.

It was thought that identifying autism features before the age of three is difficult (Moore & Goodson, 2003). However, detection of autism spectrum disorder signs before the age of three has become a trend in current research within the autism field (Landa, 2007; Cassidy et al., 2008). Moreover, recent statistics showed an increasing incidence of autism spectrum disorders (Knapp et al., 2009). According to the National Autistic Society (2011), 1 in 100 is the prevalence rate in the UK, while the Autism Society of America (2011), reported that 1 percent of the population of children in the U.S. aged between 3 and 17 have an autism spectrum disorder. The centre for Disease Control and Prevention (2011) estimated that an average of 1 in 110 children in the United States have autism. This prevalence in the increased amount of diagnosed cases could be related and interpreted within the context of the growing knowledge and understanding of the nature of autism and its characteristics, along with the emergence of more precise diagnostic criterion (Chakrabarti et al., 2005; Williams et al., 2006; Turner et al., 2006; Hertz-Picciotto and Delwiche, 2009; Matson & Kozlowski, 2011).

Indeed, several studies have been identified within the literature that have shed some light on the increased number of incidences of autism. For example, many researchers (Matson and Kozlowski, 2011; Hertz-Picciotto and Delwiche, 2009; Matson et al., 2008; Newschaffer et al., 2007; Baird et al., 2006; Wing and Potter, 2002) reported a marked increase in autism

prevalence. Dietz and colleagues (2006) and Stahmer (2007) argue that autism recognition is good, and the earlier the better. Thus, linking the importance of early identification of autism as emphasized by Dietz to previous discussions of the increasing number of autism prevalence, the concern here should be directed toward the possibilities of providing provision services to accommodate the inflation in the number of individuals being diagnosed with autism and their families. Indeed, this addresses both the need for providing services specially designed to accommodate this group of children and their families, and the gap in the literature over what is the best practical methods to provide family support and services (Matson et al., 2008; Rajendran and Mitchell, 2007; Stahmer, 2007; Shattuck and Grosse, 2007). The previous illustration could be seen as a justification for the current study's aim in providing a vision of how such supportive services can be developed and provided in the light of examining parental needs.

The following part of this review will give special attention to the efforts that been made to incorporate psychological principles to develop autism educational intervention approaches.

### **3.2.5 Educational Intervention Approaches**

Although, autism is an invisible and challenging life-long disorder, significant efforts have been made to help children who have autism cope with and adapt to their disability. This effort could be traced back to as early as the identification of autism, as it is believed that Hans Asperger opened a school for autistic psychopaths; unfortunately the school was bombed in World War II and much of Asperger's work was lost (ZenEmu, 2010). However, a great deal of research was carried out to develop educational provisions for individuals with autism which was considered to be on the top of the list of interventions which are available for this category of people (Reed et al., 2007). Generally, the aim of this provision is to not only offer effective learning opportunities that meet the individual's needs, but also as a remedial goal by addressing the triad of impairments in autism and

to try to reduce its resultant problems from being clearly manifested in child behaviours (Jordan, 2005). Various kinds of intervention approaches for autism have been developed and these have built upon different psychological theoretical perspectives. For instance, ABA (Applied Behaviour Analysis), an approach based upon behaviourist principles; TEACCH, (Treatment and Education of Autistic and related Communication handicapped Children), which was developed by Schopler in the USA in 1970 and is now used in many countries around the world (Trevarthen, et al., 1998); and PECS (Picture Exchange Communication System), a system which focuses on teaching communication skills for children who have autism (Jordan, et al., 1998).

The following is a classification for some well recognised and widely used intervention strategies within the autism domain. These approaches are based upon different psychological theories as previously stated.

#### 3.2.5.1 Interventions Based on Behavioural Principles

Applying behavioural principles to educational interventions which target the autism core deficits of social capability; communication and the ability to think flexibly have been widely used and implemented within the autism domain. The following are examples of such approaches:

- ✓ The Discrete Trail Teaching or ABA approach is based on operant conditioning principles which are based on task analysis and performance (Lovaas et al., 1987). This approach reflects a traditional ABA style in observing, identifying, defining and measuring behaviours to obtain a sound understanding of such behaviours and how the individuals' learning is influenced. Eventually this would help in designing an intervention by targeting specific goals. Indeed, applying such principles might take several forms based on intervention goals, whether to manage the child's difficult behaviour or to teach a child specific skills. Positive reinforcement used to encourage the desired behaviour or

parents ignoring the undesired behaviour are believed to be essential techniques to increase or decrease the likelihood of redirecting or discouraging behaviours according to this approach philosophy (Lovaas et al., 1974; Lovaas, 1993).

- ✓ Pivotal Response training (Koegel, 2006) is an incidental teaching and natural language paradigm. It includes the milieu teaching method and reciprocal imitation training. These approaches focus on enhancing the child's motivational ability. This reflects a more modern approach to behavioural procedures.
  
- ✓ The Picture Exchange Communication System is an augmentative communication approach based on a pictorial system which can be used as a form of communication especially for nonverbal children (Bondy & Frost, 2001).

The above discussed behavioural techniques have succeeded to a certain extent in teaching individuals with autism several skills within the autism core deficit. These have included, for example, teaching daily living skills, such as eating and dressing skills. These are successfully acquired especially by those who are on the moderate and mild autism scale of severity. The task analysis and performance techniques are found to be useful when teaching skills that are on the simple behavioural level and do not demand a high level of thinking ability.

However, more complex actions which require a high level of thinking processes are not easy tasks to acquire through such behavioural techniques. For example, acquiring social skills such as being socially engaged or being able to make friends and develop social relationships are not easily achieved through behavioural approaches. As a result, there has been criticism over the emphasis on behavioural intervention strategies.

There will now be a discussion about the limitations of the behavioural approaches to tackle autism's core deficit. In the behavioural approach, learning means a change or a development in the individual's behaviour. Similarly, if the child acquires a specific skill, this means that he or she should be able to use the skills in various situations independently. Thus, failing to demonstrate this ability means that the learning was not successful in all of its stages. This can be seen as one of the problems which face most individuals with autism. Most find a difficulty in generalising the skills that are supposed to be acquired in different situations. Furthermore, this also suggests that the behaviour is on a copying level rather than being on an understanding level. This can alternatively be expressed as being on the action phase more than on the cognitive phase. Therefore, it is possible to see this as being a generalisation dilemma which is one of the major deficits of autism. Therefore, this suggests that understanding an individual's actions and behaviour within the social context is not achievable through a behavioural approach.

Consequently, this raises a very important question regarding how behavioural approaches could be modified or improved in order to handle the skills generalisation in daily life circumstances for individuals with autism (Gould et al., 2011). In addition to that, the behavioural approach seems to focus on the current behaviour more than the past and future behaviours that are linked to the current one that is under consideration. This might be interpreted as if each behaviour is treated independently. This notion could be a reflection of one of the behavioural main principles which emphasises that in order for any behaviour to be acquired the same occurrence behavioural sequence should exist.

The behavioural approach could be useful in teaching specific simple basic skills, in which an individual is exposed to systematic behavioural procedures in order to learn new skills. However, stretching an individual's capability will be limited and this might limit the child's chances to think creatively, as the behavioural approach is considered as outside stimuli

more than inside ones. In fact, this explains its success in teaching the basic skills more than any other social and creative skills. This also could be regarded as another criticism over using reinforcement as another behavioural principle in which such principles are mainly dependent on tangible outside reinforcements, such as food, toys etc. This also might be a problematic issue within the autism domain in which individuals might lack the inner motivation to do certain things, such as being socially engaged with others. Again, behavioural approaches do not effectively confront such difficulties in autism.

Another concern regarding implementing behavioural approaches is that such strategies require highly qualified teachers in order to ensure that the approach is applied correctly in order to achieve the optimal required result. This means that some teachers might struggle while applying behavioural approaches. Moreover, for caregivers of individuals with autism following such an approach might not be an easy task. Offering training for teachers and caregivers seems to be a productive idea. However, it is time consuming and they might be confronted with several difficulties, such as a lack of qualified trainers and the lack of a willingness to learn by the trainees. Therefore, one can conclude that behavioural approach strategies do not offer practical techniques in which the caregivers or teachers could implement simply.

### 3.2.5.2 Interventions Based on Developmental and Sensory Integration Approaches

- ❖ Floor time (Greenspan and Shanker, 2007); The Denver Model (Rogers and Lewis, 1989); Emotional Regulation and Transactional Support (SCERTS Model) (Parry, 2006). These approaches focus on an enhanced social and communicative ability and a self-regulatory and discovery process through the use of the natural environment and developing relationships (Landa, 2007; Eikeseth et al., 2007; Vismara et al., 2009).

- ❖ Integrated Movement therapy is another intervention based on yoga. It aims to address the sensory integration deficit that is associated with autism (Kenny, 2002).
- ❖ Massage therapy has a focus on sensory stimulation with the intention of promoting joint attention (Solomons, 2005).

### 3.2.5.3 Intervention Based on Environment Altering or Engineering

#### 3.2.5.3.1 The TEACCH approach - Treatment and Education of Autistic and related Communication-handicapped Children

TEACCH is based on the principle that understanding that an individual's needs, interests and strengths, rather than putting an emphasis on the deficits, are essential in order to develop intervention strategies. This approach focuses on addressing the autism deficit based on visual mediated learning and learning within an organised environment. This approach was suggested in 1966 by Eric Schopler (Schopler and Mesibov, 1983).

Having a clear structure is a TEACCH characteristic which reflects its philosophy of developing a better understanding of an individual with autism and systematising his /her environment by making it predictable and controlled. Thus, this systematic method claims that it addresses the problems that people with autism experience rather than dealing with autism directly (Jordan & Jones, 1999). Mesibov and Howley (2003: p.8) stated that '*structured teaching is designed to address the major neurological differences in autism*'. These differences include understanding receptive language; having difficulty in expressive communication; experiencing difficulty with organisation; and having difficulty in attention. Such obstacles result in students with autism having difficulty in understanding and controlling their environment.

In an attempt to review the research evidence for the effectiveness of TEACCH Schopler, Mesibov and their colleagues have evaluated the

TEACCH programme via nine studies undertaken between 1981 and 2003. Those studies show that individuals with autism who follow the TEACCH programme made significant progress in developing appropriate behaviour, communication and imitation and their families were reported as being satisfied by the regime (Jordan & Jones, 1999). Despite this evidence, in 1998 Jordan et al. reported that:

‘although TEACCH is one of the longest-established programmes, with an international influence, there has been surprisingly little done to evaluate the programme in terms of outcomes’ (p, 71).

Moreover, they criticise the objectivity of the results because most of the findings favour and validate TEACCH, but as the studies were conducted by the people who run the programme, they cannot be regarded as independent and objective evaluators. However, this does not mean that the programme itself is not valid or successful, but it does suggest that further research from independent evaluators needs to be done in order to evaluate the programme objectively. However, the influence of TEACCH worldwide has strong evidence of its success in helping those with autism.

#### 3.2.5.3.2 Daily Life Therapy

The Daily Life Therapy (Higashi) approach is a systematic group-oriented approach that aims to promote an individual’s integration and independence so that individuals would develop daily living skills through repetitive routines within the group activities. This approach is a combination of eastern philosophy and Japanese pedagogy. It was developed by Dr. Kiyoko Kitahara more than thirty years ago (Quill et al., 1989).

The previously highlighted intervention approaches are some of the most visible and frequently cited educational interventions for individuals with autism. Thus, regardless that each one of these has been established based on a specific theoretical framework they all share almost one aim in general

which is enhancing an individual's learning and development. However, intervention effectiveness is wide-ranging, as some of these approaches (ABA and TEACCH) have reported, encouraging empirical evidence regarding their effectiveness (Eikeseth, 2008). Others such as the Integrated Movement therapy and Higashi are still considered to be controversial due to their limited or lack of evidence in their past practices (Reed and Osborne 2007).

### **3.3 Early intervention**

After providing some current educational intervention approaches that are in practice, the attention will focus next on early intervention in particular. Therefore, the early intervention's importance, the current intervention implementations and criticisms over an early intervention programme's effectiveness are considered.

#### **3.3.1 Importance of Early intervention**

Early intervention programmes have the same general educational intervention aims in targeting individuals with a disability for both educational and clinical needs. The role of this service is to accommodate both the child at risk or that has been diagnosed with a disability and their family by providing them with psychological and educational support as well as any assistance that they need at the early stage of diagnosis. Shields (2001) argued that appropriate early intervention should be provided immediately after the child is diagnosed as such a service would bridge the gap between and for obtaining an educational placement. Early intervention is a multi-disciplinary service, where more than one intervention approaches or services would be provided for the child and the family as required. This might include psychological services, diagnosis and assessment, consultations, transportation, family training, occupational therapy, speech therapy, dietary therapy, medication therapy; behavioural modification therapy and play therapy, etc.

Indeed, the importance of such services could be evaluated through different phases that emphasise the role of the intervention programmes in first, enhancing the child's developmental process via addressing his/her deficit; second, enhancing family adjustment; and finally, contributing in knowledge growth and research implications within this particular domain, especially in the light of the growing number of autism incidences (Kochanek & Buka, 1998). In fact, from a developmental perspective it is widely believed that the first five years of a child's life, play time has an important role on the child's later development. According to Turner et al. (2006) children with developmental delay who are exposed to early intervention programmes are more likely to gain more coping strategies later in their life. Researchers also demonstrated that individuals with autism experience developmental delay in acquiring early social communicative skills. Consequently, they need intervention strategies that enhance their ability to gain the necessary skills that they need throughout their life in the light of the deficiency (Koegel et al., 2001; Jordan, 2005; Jones et al., 2006).

### **3.3.2 Early Intervention Implementations**

Moving from the idea of early intervention significance to the crucial part where the attention is focussed on how such programmes work and are implemented within the context of a natural environment. Early intervention usually accommodates children aged between 2 and 5 years and rarely caters to the age of one with regards to autism's diagnostic reliability at this early time. Although, early intervention services provided for individuals with autism are almost similar to those provided in general, there is a slight difference in their nature from the traditional ones. For example, unlike early intervention that traditionally provided for other developmentally delayed conditions that are characterised by a relatively low intensity in nature and report less than 2 hours per week of services (Kochanek and Buka, 1998), early intervention programmes for children with autism are very intensive and diverse in nature. For example, ABA recommends up to 40 hours a week in order to gain a satisfactory outcome

from the intervention (Lovaas, 1993). Other studies have set guidelines for early intervention services for young children with a developmental disability that suggest they reported a higher time intensity as one of the important components of early intervention guidelines for individuals with autism (Noyes-Grosser et al., 2005). A one-to-one teaching strategy and the behavioural principles implementation are other issues that characterised most intervention approaches provided for an individual with autism (Gould et al., 2011). The presence of such intervention characteristics is due to the complex nature of autism as a triad of impairments that affects a child's development in three different areas; socialisation, communication and thinking flexibly, which in turn would call for intensive intervention to address such complexity.

In the light of an existing early childhood intervention programmes that caters for children with disabilities, both behavioural and developmental approaches are incorporated in providing early intervention to target a broad range of child limited skills (Boulware et al., 2006). However, differences exist between these intervention theoretical approaches. According to the National Research Council (2001), the early intervention programme has to have fundamental elements. These include:

1. That the intervention should occur as early as possible in the child's life.
2. That the intervention should be intensive in nature.
3. That the parents should be involved as facilitators in their child's intervention.
4. That the communication and play skills should be intervention's main targets.
5. That the child's individual profile should direct intervention goals.
6. That the intervention should follow a systematic approach to achieve its goals.

Indeed, it is almost similar within the context of autism deficit. However, special emphasis was given to specific skills which have been identified to

be a central focus of early intervention programmes for children with autism (McConachie and Diggle, 2007). The following skills are regularly the main components of the intervention programmes: social communicative skills which include initiating and responding to joint attention and eye contact, language skills, imitation skills, play skills and self-determination skills, such as decision-making and problem solving skills (McConnell, 2002; Jones and Carr, 2004; Ingersoll & Schreibman, 2006; Whalen et al., 2006; Toth et al., 2006; Mulhearn and Blasco et al., 2006). These skills are considered to be prerequisite skills to enhance the child's development. Indeed, impairment in such features that are exhibited in autism is believed to affect other areas of development (Oosterling et al., 2010). The following section will exemplify some research evidence regarding these skills and their role in the child's development, and their potential for development within intervention strategies. These include joint attention, imitation and play skills.

#### 3.3.2.1 Joint Attention

Joint attention is one of the recommended skills which need to be included within early intervention programmes for individuals with autism. This is because joint attention deficit could be seen not only as an early indicator of autism but also discriminates individuals with autism from other developmentally delayed children (Kasari et al., 2010; Sullivan et al., 2007; Toth et al., 2006; Solomons, 2005; Dawson et al., 2004). Moreover, such a deficit has a significant impact on a child's cognition, social and language development (Schertz and Odom, 2004; Warreyn et al., 2005). Furthermore, this deficit might limit the child's social learning opportunities which could lead to social cognition delay (Sullivan et al., 2007).

Joint attention consists of the individual's ability to share attention with others via initiating attention and responding to attention. Studying joint attention however, is a challenge for researchers because this ability involves highly cognitive representations. Nevertheless, research findings which consider joint attention within their intervention strategies indicate

that this approach could be taught and improved via interventions (Rocha et al., 2007; Kasari et al., 2006; Toth et al., 2006; Hannah et al., 2004). Kasari et al. (2006) in their study into acquiring joint attention, found that children with autism who are exposed to this intervention, exhibited improvement in responding to joint attention in comparison to the study control group.

### 3.3.2.2 Imitation Play

Imitation is the ability to copy and perform observed actions in the same or a different social context. It plays an important role in the child's cognitive and social development. Therefore, it is another recommended targeted skill which should be considered within an early intervention programme. Imitation is considered to be one of the early developmental innate abilities; however, it is also thought to be one of autism's deficiencies (Ingersoll and Schreibman, 2006). Some studies suggest that the imitation deficit decreases with age in individuals with autism (Warreyn et al., 2005).

### 3.3.2.3 Playtime Skills

Playtime skills are also a suggested focus for early intervention programmes. This is because it constitutes another developmental problem in young children with autism which impacts on their cognitive development. Here, playtime skills are understood to be a good sign of a child's understanding of the mental state and behaviour of others, which helps in developing a better cognitive and social ability (Pierce et al., 2009; Landa, 2007; Kasari et al., 2006) Indeed, play is a source of experiences which normally exposes a child to a wide range of social contexts (Toth et al., 2006).

Several studies have examined playtime skills in autism in terms of the way play is manifested, its impact and the ways of addressing this deficit in children with autism. Warreyn et al. (2005) found in their study of early social communicative behaviours of nursery aged children with autism while interacting with their mothers, that smaller amounts of functional

play, less symbolic play and more non-functional play were exhibited by these children in comparison to the study's control group. However, they also suggest that fewer problems were displayed by children with autism in structured play situations. These results suggest that children with autism might have some form of playtime skills; however, these skills are rather limited.

Indeed, some intervention programmes studies address one skill while other programmes give attention to more than one skill. Based upon current practice within the educational domain, researchers have examined different educational approaches and teaching strategies in developing early intervention programmes designed specifically for children with autism aged 2-5. Generally, addressing these previous skills may take two dimensions: child-centred services and/or home-based services via adapting different educational intervention strategies. Some research has been conducted in school settings for pre-school aged children, while others have been undertaken in the home setting. Here are some examples of strategies that have been documented in the literature; discrete trial instruction, pivotal response training strategies, incidental teaching, milieu teaching, peer-mediated intervention, sibling-mediated intervention, floor time strategies, social stories approach, massage therapy, musical therapy and play therapy (Mahoney and Perales, 2003; Schertz and Odom, 2004; Jones et al., 2006; Ingersoll & Dvortcsak, 2006; Matson et al., 2007; Gulsrud et al., 2007; Vismara and Lyons, 2007).

However, there is no research evidence that favours one approach over another (Reichow et al., 2008). Moreover, firstly, all of them prove to have an impact on addressing autism deficit, and secondly, they have common features in terms of one-to-one teaching techniques and intensively applied systems (Reed et al., 2007). Yet, it is widely agreed within the educational domain that not only is there no specific approach that could fit all children but there is also no one method that could fit an individual's different developmental levels (Dymond et al., 2007; Reed et al., 2007). This might

be due to different reasons stemming from their individuality, such as individual differences, level of autism severity and IQ ability, while others might be related to intervention effectiveness (Gould, 2011; Ben Itzhak and Zachor, 2010.) Such programs must take into account that autism deficit affects individuals differently through his/her life span, for example, what might work for an individual during childhood might not be applicable in their teenage years or adulthood. For this reason, different strategies must be implemented within the intervention programmes on an individual basis, and in such cases, results are promising and indicate the effectiveness of such intervention strategies at this early age (Gutstein et al., 2007; Reed et al., 2007).

### **3.3.3 Criticisms over early intervention programme effectiveness**

Although there is a general consensus about the importance of early intervention programmes for individuals with autism, several criticisms have been raised about such services. One such criticism is that implementing any intervention approach usually aims to impact positively on the child's development. However, the evaluation of intervention effectiveness is considered to be problematic. In fact, this could be seen as one of the criticisms about early intervention programme effectiveness (Noyes-Grosser et al., 2005; Cassidy et al., 2008). Evidence from the research literature suggests that specific intervention approaches such as TEACCH or APA could be effective with children with autism (Eikeseth et al., 2007; Rogers and Vismara, 2008). However, the longitudinal studies that can give trend evidence about the long-term effects of any named approach on child improvement remains limited. Moreover, specific details concerning which approach could be most useful with particular groups of children or families are inadequate (Richer and Sheila, 2001).

Another concern is that evaluating any approach means using particular assessment tools. Here, there is criticism over assessment tools that are currently being used to assess a child's progress, particularly in terms of their reliability and relevancy. In other words, such assessment tools might

not be reliable, valid or relevant to the specific intervention approach. Therefore, intervention approach outcomes might be questionable (Cassidy et al., 2008).

Another area of criticism over early intervention effectiveness is the difficulty in differentiating between maturation and the impact of the intervention on a child's progress. Yet few studies have investigated this issue and this concern therefore, appears to have been neglected (Goin-Kochel et al., 2009). Some researchers also report that some early intervention providers do not have access to recent research evidence regarding current practice about early intervention approaches for children with autism (Ingersoll & Dvortcsak, 2006; Arlene et al., 2008). This also could be regarded as an important criticism as this might raise questions over early intervention services being up-to-date and effective.

Yet, addressing such previously discussed issues is almost impossible in this study. However, one of the present study's aims is to develop an early intervention home-based programme for individuals with autism based on current research findings within the autism domain. This would target specific groups of children and families who have the same status in terms of the child age group, recent diagnosis and who do not receive educational intervention for more than six months.

### **3.4 Parental training**

Parental training is a type of service that is provided under the umbrella of early intervention services. Indeed, parental involvement in their child's intervention programme it is not a new perspective in the field of education, and its history can be traced back several decades (Rutter and Schopler, 1978). Generally parental training as presented in the literature aims to:

- ❖ Equip caregivers with the necessary knowledge and skills they need in order to be able to deal with their children more comfortably on a daily basis.

- ❖ Enhance parental confidence in helping their child.
- ❖ Provide consultation so parents would be able to take the necessary actions for their child's future, such as choosing the appropriate intervention based on the consultation.
- ❖ Reduce parental stress levels because parents need help in setting realistic expectations about their child's performance rather than maintaining either unrealistically high or low expectations. This might prevent parents from being vulnerable to disappointment in the future.

Therefore, the following discussion examines the current understanding of such a service, its importance, implementation and effectiveness.

### **3.4.1 Importance of Parental Training**

It has been widely reported in the literature that parental training is one of the important methods in promoting skills, generalisation, and behaviour maintenance in children with autism (Ingersoll & Dvortcsak, 2006). According to McConachie and Diggle, (2007), the vast majority of intervention programmes for individuals with autism involve the parents to a greater or lesser extent within the programme implementation. This is because the family context has a crucial influence on the first stage of the child's development (The National Research Council, 2001; Boulware et al., 2006). Wallace et al., (2010) argued that parental involvement in their child's intervention is one of the most effective intervention procedures that is provided for individuals with autism. Lovaas and colleagues (1973) emphasised the importance of training parents as intervention providers. They noted that children who were exposed to intervention in both the home and school settings via their trained parents, were better in maintaining the learned skills when compared to those who were only trained in an institutional setting. Several other reasons have been highlighted within the literature, emphasising the idea that parental training serves to benefit both the family and the child. As such training equips the family with the skills that they need to parent children with developmental delay in an effective

way. Consequently, the child would be exposed to the intervention as early as possible. Indeed, within the context of the child's benefit, research has reported an increase in the child's communication skills, both verbal and non-verbal (Coolican et al., 2010; Vismara et al., 2009; Gutstein et al., 2007), and a decrease in inappropriate behaviour (Pillay et al., 2011).

Numerous studies have reported that parents with children who have autism are more vulnerable to develop stress (Dillenburger et al., 2010). For example, a comparative study conducted by Hoffman et al. (2009) between the mothers of children diagnosed with autism and the mothers of typically developing children, reported that the mothers of the children with autism suffer from significantly higher levels of stress when compared to the mothers of typically developing children. Several other studies reported similar results, that the mothers of children with autism experience higher levels of stress than caregivers of typically developing children and children with another disability, such as Down's syndrome (Baker-Ericzén et al., 2005). Davis and Carter (2008) suggested that there is a relationship between the behaviour of the children with autism and the parents' stress level. Jones (2006) identified within her study several reasons that might lead to parental stress, as follows:

- ✓ Daily management.
- ✓ Impermanent severity levels.
- ✓ Occurrence of maladaptive behaviour.
- ✓ Absence of treatment and agreement between professionals about effective intervention.
- ✓ Child prognosis uncertainty.
- ✓ The complexity of the diagnosis process. This can include a delay in a diagnosis for the individual with mild signs of autism and also the stress experienced by parents between their initial anxiety and the final diagnosis.
- ✓ Financial problems.

Other reasons that have been documented in the literature include:

- ✓ A lack of knowledge about what autism means.
- ✓ A shortage of services and qualified professionals.
- ✓ A limited social life and restricted daily activities (Dillenburger et al., 2010; Quintero & McIntyre, 2010).

Moreover, the difficulty associated with the period following the diagnosis would justify the importance of providing such training within the context of early intervention services. In terms of the advantages of training for the parents, several studies reported improving parental optimism in regard to their ability in enhancing the child's development after being exposed to parental training (Whittingham et al., 2009; Aldred et al., 2004). Despite the negative feelings such as denial, shock and wariness that arise at this difficult period, the parents' motivation to help and support their children would be at a high level (Vismara et al., 2009). Therefore, investing in and making the best use of such motivation is fairly important in enhancing positive feelings, which in turn would affect the parents' mental health, which would again in turn impact upon the child's development (Osborne et al., 2008).

Another advantage that is reported by various studies is that parental training helps towards improving the quality of life for the parents by reducing the parental stress levels (Pillay et al., 2011; Boulware et al., 2006; Tonge et al., 2006). Indeed, parental stress levels are not the only aspect of parental difficulties that have been documented in the literature, as there is a growing body of research literature that has identified different aspects of the emotional impact on parents as a result of parenting a child with autism. For example, Hasting (2008) reported that parents of children with autism appear to be vulnerable to a decrease in their psychological well-being. Other emotional symptoms that the parents of children with autism might be at risk of developing include depression (Benson and Karlof, 2009), psychological distress (Yamada et al., 2007), physical and mental health

problems (Montes and Halterman, 2007) and a significant increase in maternal emotional disorders (Totsika et al, .2011). Accordingly, it appears that parents of children with autism are at risk of experiencing poorer mental health and this would call for special support and services to improve and empower their own psychological well-being. Thus, providing parental training immediately after receiving the diagnosis helps the parents to manage their time more efficiently by making an action plan to cater to their child's needs and deficiencies, rather than waiting for a long time to establish an educational setting for the child.

In addition, the significance of parental training could also be seen from different angles and within the context of the accessibility of early diagnosis as well as the increasing incidence of autism. Indeed, the current services are facing a challenge in accommodating such inflation levels (Dymond et al., 2007). Thus, parental training could be seen as one way to face the challenge of the limitations of the current intervention services by educating the parents with the necessary skills (Coolican et al., 2010). Indeed, the previously discussed reasons would justify the importance of providing parental training in general and post receiving the diagnosis in particular.

### **3.4.2 Implementations of Parental Training**

As stated previously, early intervention programmes can be implemented at school or at home or may be supported in both settings. Such programmes, supported by both professionals and trained parents, are able to implement the programme principles regardless of any approaches or educational methods that are being applied. Several studies within the literature have been recognized as showing an interest in developing a parental course and examining the effectiveness of parental involvement in educating their children. However, to date there are only a few published parental training courses that have specifically targeted the novice mothers of children newly diagnosed with autism. Moreover, even with the existence of such courses, they are limited in terms of providing a detailed description of the programme components, the delivery approach or the programme

effectiveness (Marcynyszyn et al., 2011; Wallace et al., 2010). According to Reichow and Volkmar's (2009) study, which was based on four studies of preschool children, the best evidence indicated that interventions that aimed to increase social behaviour for individuals with autism, found that parental training is considered to be one of the main intervention approaches. However, according to this study, the parental training was not examined extensively. Indeed, similar to the fact that there is less agreement on which intervention approach is effective for individuals with autism, the controversy over parental training delivery approaches also exists.

Several delivery approaches have been identified within the literature. Some criticisms regarding current parental courses include the small sample size and focusing on teaching one particular intervention technique to parents, such as for instance ABA, and then examining its effectiveness on the child's development (Oosterling et al., 2010). Some approaches are based on a didactic approach, while others favour the interactive approach or one-on-one coaching or even a combination of both. Some parental training is conducted individually in a centre-based setting or in a home-setting, whereas others might be conducted as group training. Wallace et al. (2010) argue that comparative studies that examine the effectiveness of parental training delivery approaches are essential in order to determine the best way to help and support the parents. For this reason, the next section focuses on the effectiveness of parental training programs.

### **3.4.3 Effectiveness of Parental Training**

In order to understand the effectiveness of any given program, it is essential to discuss current research evidence in relation to its effectiveness. In a review conducted by McConachie and Diggle (2007), they reported that parental training for their children with autism could be understood within the context of three questions based on knowledge from the research evidence. These questions are (McConachie and Diggle, 2007, p127):

- a. Can the intervention work?
- b. Does the intervention work?

c. Does the intervention work in practice?

They concluded that training parents in targeted skills might have a positive effect on the system's capacity to respond to demands for improved services for the child's disability. Their results indicated that parental intervention can and does work since improvement in the children's social communication skills and parental knowledge and performance have been reported in several reviewed pieces of research within their studies. However, they questioned the effectiveness of such parental intervention due to the design of most of the studies. They suggest that most of the studies encountered several limitations, such as a small sample size; a relatively short-term assessment and limited effective caregiver intervention options to choose from.

Recent studies conducted on providing a parental training programme have been identified as having conflicting results, where some were promising and supported the importance of parental training in enhancing child development, whilst others showed no significant differences in child development following parental exposure to the training programme. For example, Oosterling et al.'s (2010) study aimed to replicate the promising results in a Dutch community that were shown in the English pilot study by Drew et al. (2002). The previous pilot was a randomized, controlled trial of the *Focus parent-training programme* for preschool children with autism. The training was a 12 month long home-based parent-training programme that adapted a consultant model in which the parents acted as the child's therapist and the professional as a consultant. An election approach was applied to promote child development within the context of social and communicative behaviours. According to the Dutch study, no significant results were found in the children's language development one year after the start of the intervention. The researchers interpreted that the differences in the identified results from both of the studies as being due to the differences in the study context, in which the latest results were conducted in Dutch community care.

On the other hand, in a recent pilot study conducted by Wong and Kwan (2010) a promising result was reported. They designed a two-week short-term intensive training programme on communication and social interaction for the children with autism, with the participation of the primary caregivers. The trainers trained the children in using eye-contact, gestures and vocalisation, along with teaching the parents to use these corresponding techniques at home. The results showed that at the child's level there were improvements in language, communication, reciprocal social interaction and symbolic play. At the parental level, the parents noticed improvements in the child's language and social interaction, and a reduction in their own stress levels. Regardless of this promising result, the study encountered several limitations in terms of its nature as a pilot study incorporating a small sample size and the lack of using a control group.

Whittingham and colleagues (2009) in a randomized controlled trial study examined the effectiveness of *Stepping Stones Triple P* on fifty-nine families with a child with autism in the age range of between 2 and 9. *Stepping Stones Triple P* is a parenting training programme based on behavioural intervention strategies targeting parenting practice by encouraging the parents to develop their knowledge, skills and confidence in a nine-week time period, through applying both group and individual delivery approaches. Similarly, promising results were reported by the parents, as having significant improvements in both the child's behaviour and the parenting style. Although the study sample was relatively large, a limitation exists as the parental reports were the only measure to examine the effectiveness of the treatment.

Within the same context of investigating the effectiveness of parental training programmes in supporting parents of children with autism, Nefdt and colleagues (2010) applied a self-directed learning approach on 27 primary caregivers of children with autism aged five years and less. They aimed to examine whether applying a self-directed approach would lead to changes in the behaviour of parents and their children. So, this approach

would serve as an initial step towards providing an introductory training to the parents who have to wait for intervention services after receiving the diagnosis, and who are in an area where intervention services are not easily accessible. The idea of the programme is based on providing the parents with brief parental training, utilizing an interactive DVD along with an accompanying manual covering the Pivotal Response Training (PRT) as a tool to provide caregivers with an introductory knowledge about how to help their children using an evidence-based procedure. The findings indicated significant differences between the treatment group and the control group in acquiring the specified methods. The treatment groups were more confident during parent-child interaction and their children's ability to use functional verbal utterance increased.

Thus, the results of the study would suggest a cost-effective method that would confront the challenge of providing effective intervention services as early as possible, and after receiving the diagnosis, not only for those who are on the waiting list but also for those who have no easy access to services. However, the study is still limited in terms of: first, providing specific intervention techniques (PRT) that aim to improve the child's verbal competence through parent-child interaction; second, a lack of access to immediate feedback from professionals; third, limiting the parents' chance of communicating with others who are in a similar situation and exchanging concerns and experiences. Therefore, it could be recommended that using such training would be more effective if it is accompanied by coaching strategies.

Another experimental study conducted by Vismara et al. (2009) aimed to provide intervention for eight parents of children aged 10-36 months, following the child's diagnosis. The parents were trained to deliver the teaching procedures of the Early Start Denver Model and the Pivotal Response Training across 12 weekly sessions of one hour each. Parental acquisition of the teaching skills and the change in the child's social communicative behaviours were assessed using several tools at the baseline

and a follow-up after the 12 weeks intervention. The results showed that the parents acquired the skills before the end of the intervention at weeks six and seven, and the children continued to change and grow in social communicative behaviours. Indeed, this result is promising and consistent with what has been mentioned in the literature in terms of parental acquisition of teaching skills and the child's improvement on the communicative and behavioural level. However, Fava and Strauss (2011) criticised this study for the lack of facilitation of generalisation and maintenance. The generalisation of the skills across natural settings provides a diversity of learning opportunities and encourages learning within normal family activities (Matson and Smith, 2008).

An examination of the literature on parental training programmes for individuals with autism might suggest that behavioural approaches such as 'Discrete Trial Training' and 'Pivotal Response Training' are the most popular training strategies currently offered to caregivers (Coolican, 2010; Crockett, 2007; Nefdt et al., 2010). Although, the parents acquire the behavioural strategies over a short period of time, Rocha et al. (2007) suggest that the long term effects and outcomes of implementing such strategies with their children are rarely assessed. Moreover, the intervention's impact on the family is also rarely addressed within the research studies, as most current research is concerned with the impact of the assigned treatment on the child's outcomes (Cassidy et al., 2008).

A naturalistic approach was also frequently used within the parental training context with the aim of providing parents with structural interactions techniques (Ingersoll and Gergans, 2007). Indeed, this type of intervention is recommended and popular for early childhood education (Reichow and Volkmar, 2009). Schertz et al. (2004) also reported in their review that, of the existing interventions which examine joint attention as one of the primary intervention targeted skills, 'floor time', responsive teaching and 'Meditational Intervention for Sensitizing Caregivers' approaches might be an effective group of approaches that are able to capitalise on the parent-

child relationship. These approaches emphasise the quality of the parent-child relationship (Hannah et al., 2004). They regard parental implementation of the intervention as a primary component of intervention, rather than supplementary one.

Accordingly, although longitudinal studies examining the effectiveness of parental training programme are still limited, the previous illustration of a current study result provides a strong submission over its effectiveness. It encourages researchers to do more work and investigate possibilities of developing and examining such services.

#### **3.4.4 Difficulties of Establishing and Running Parental Training**

The above studies lend weight to the current study's focus of attention, which is the importance of considering the parental perspectives, not only in terms of the 'delivery' of early intervention programme, but also in the development of such services. Keeping in mind that the main aim of this study is to identify the child's needs within the family context and to provide the family with both the knowledge they need and with practical and easy strategies to implement and enhance the child's development within the communicative domain that is affected by autism. Goin-Kochel and colleagues (2009) argue that

'treatments that do not mesh with a family's beliefs, priorities, and daily routine will either not be attempted or not tried for very long and, thus, will not be viewed as efficacious' (p.3).

Based on the earlier illustration of the current practices and the effectiveness of providing a training course for the parents, it could be anticipated that developing and delivering such a course is not an easy task, as several factors need to be considered to do so. The following are some difficulties which might emerge when designing a training programme for parents:

- ✓ The diversity in parental perspectives, feelings, requirements and understandings of the situation. Jones et al. (2006) reported that one of the important findings of her study is that mothers developed complex attributions to explain their child's autism diagnosis. Therefore, designing a fixed training programme was impossible, especially since there is not any one approach that could fit all children and all families' needs. The diversity in intervention approaches makes it difficult to choose from.
- ✓ The scarcity of longitudinal studies on examining parental training effectiveness (Reichow and Volkmar, 2009).
- ✓ The diversity in the level of parental commitment to attend and complete all sessions of a programme, would affect their understanding and ability to link the information and skills together (Kasari, 2010).
- ✓ Criticism within the field over the effectiveness of parent-mediated early intervention programmes for children with autism. This criticism includes several difficulties: first, parental training is time consuming because the training outcomes should justify the time and effort taken by both the parent as a trainee and the professional as a trainer (Wallen and Stagnitti, 2006).
- ✓ Training outcomes are affected by the quality of the trainer (Johnson et al., 2007; Bryson et al., 2007).
- ✓ Training the parents might lead to an increase in their stress levels due to an increase in the workload and demand over them (Wallen and Stagnitti, 2006).

### **3.4.5 The Service Providers and the Professionals' View on Parental Involvement**

Researchers have been attracted to the philosophy and principles of several early intervention programmes. However, the vast majority of studies conducted on such early intervention programmes have focussed on

programme effectiveness and the child's outcomes (Grindle et al., 2008; Turnbull et al., 2007). The impact of EIPs (Early Intervention Programmes) on the family is rarely examined, apart from considering parental satisfaction. Moreover, examining the parental experience of having a child with autism and its impact on the parental needs, concerns and specialist skills are usually absent within most studies (Dillenburger et al., 2010). Parents are generally treated within this perspective as tools to help the child, rather than being actively involved in their child's development and accepting him/her as s/he is. Grindle et al. (2008), in their study concerned with examining the parental experience of home-based applied behaviour analysis, raised the critical issue that being aware of the family experience regarding the programme implementation might contribute positively to improve its effectiveness.

Another study concerning the family experience was conducted by Turnbull et al. (2007). They aimed to identify the nature of the services offered to families via early intervention programmes for children with a variety of special needs. The researchers argue that there is a gap in the policy and the practice related to the early intervention. Furthermore, they argue that there is also an absence of a clear understanding of what support and services should be provided for families with children who have disabilities from birth to the age of five. According to their study, the current professional focus is directed toward the process of providing the services, in other words, how the services should be delivered. However, Turnbull et al. (2007) consider that a more appropriate approach should be about developing family-centred services, where the family's choices are accepted by the professionals. Webster et al. (2003) argue that considering the user perspectives about the impact of interventions in everyday settings is imperative. Therefore, service providers should ask what type of services and early intervention programmes could be offered to a child's caregivers. Such an initiative from the service providers might help in developing a conceptual framework for what type of services and support could be offered via early intervention programmes.

Keilty and Galvin (2006) emphasised within their study the adaptation processes which families developed in order to encourage their child's learning. They argue that parents develop their own systems based on their own knowledge and understanding of their own child. They also considered that the parents might not know that they are developing an adaptation method or the reasons for developing them. Therefore, their study emphasised the importance of professional awareness about family culture, understanding and efforts to promote their child's learning in order for them to be able to help and build upon what the caregivers are already doing.

### **3.4.6 Currently Provided Parental Training Courses**

In examining the literature, limited findings were reported in terms of currently provided parental training courses. Some of these programmes have been designed specifically for the parents of individuals with autism that consider the autism deficit such as Early Bird and the Son-Rise programmes. Others were adapted to fit autism from early intervention programmes provided for other developmentally delays, such as the Portage and Hanen programmes. The main aim of such training is mainly to adapt some intervention strategies so it could be applied within the context of an early intervention home-based setting. Following are some examples of such programmes.

#### **3.4.6.1 Early Bird Programme**

The National Autistic Society (NAS) Early Bird Programme is a short-term early intervention package targeting parents of pre-school children diagnosed with autism. It is a three-month training programme addressing both the needs of the parents and their children. The programme aims to build parental confidence by providing the parent with the following: an explanation of the underlying deficit of autism, ways of establishing a means of communication with the child and examining underlying triggers of the child's difficult behaviours. The philosophy behind addressing autism

deficit first, followed by communication and then the underlying triggers of difficult behaviour is providing the parent with the knowledge about autism first. Consequently, acquiring such an understanding would help them to understand the deficit that the child encounters in term of communication, which in turn would lead to the development of difficult behaviours. Thus, the parent would be able to support their children in a natural environment.

No single approach or techniques were provided through the training; instead a diverse collection of best practice within the autism domain incorporated these. They included the SPELL framework which is a short form of Structure, Positive, Empathy, Low arousal and Links, TEACCH, which stands for Treatment and Education of Autistic and Communication handicapped Children approach, and PECS (Picture Exchange Communication System) (Shields, 2001; NAS, 2011). Thus, there are limited studies which evaluated the training programme components, delivery approach and effectiveness (Pillay et al., 2011).

#### 3.4.6.2 Options

Barry and Samahria Kufman were the Options programme developers. The couple were advised to institutionalize their child, Raun, after being diagnosed as severely autistic. As a result, they designed a home-based programme to help Raun. Subsequent to the child's recovery, the parent documented their efforts in helping their child in a book, *A Miracle to Believe in*, which was published in 1981. In response to parents of children with autism demands for help, the Kufmans established The Option Institute and the Autism Treatment Centre of America. Through the institution, they offer three levels of parental training programmes. These are:

##### 3.4.6.2.1 The Start-Up Programme: Level 1

This is a foundational five-day training programme aimed to equipped parents with the tools to design and implement their own home programme. The program covered the following topics: speech and language

development, behaviour management and enhancing motivation and empowerment. The delivery approach consists of using several methods such as slides, videos, lectures, activities, question and answer sessions, creating a playroom and a manual of the key elements of *The Son-Rise Program* to refer to at home.

#### 3.4.6.2.2 The Intensive Programme: Level 2

This is an advanced version of Son-Rise. It is a one- week course in which both the child and their caregiver live and work in the Son-Rise house. An individual educational programme is designed to fit the child's needs. By the end of the programme, the child would receive 35 hours of intensive interaction. The teaching method incorporates a number of procedures, including: observing staff working with the child to learn the skills, parents working in a one-to-one practical situation in which they work with the child to develop confidence-building to manage a program at home, and videos are also used for training purposes.

#### 3.4.6.2.3 The Maximum Impact Programme: Level 3

This is an intensive advanced version of the Start-up programme provided for those parents who have completed the Start-up foundational programme. A similar teaching style is applied, plus the parents are entitled to free consultations before and during the training and further telephone support after completion.

The programme's philosophy emphasizes on several principles, such as believing in the child's ability, addressing the role of love and acceptance and considering parents as an important resource for a child. Enhancing social and emotional development skills via play-based methods are the main targets of the programme<sup>31</sup>. Indeed, the claim over programme

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<sup>31</sup>[http://www.autismtreatmentcenter.org/contents/about\\_son-rise/history\\_of\\_the\\_son-rise\\_program.php](http://www.autismtreatmentcenter.org/contents/about_son-rise/history_of_the_son-rise_program.php)

effectiveness is over-shadowed by its lack of research evidence to support its successes (Pillay et al., 2011).

#### 3.4.6.3 The Portage

The National Portage Association provides the portage home-visiting educational services. Pre-school children with additional support needs and their families are the services targeted group. The programme, via regular home visits by a Portage visitor, aims to:

- ✓ Support the development of play, communication, relationships, and learning for young children within the family.
- ✓ Support the child and family's participation and inclusion in the community.
- ✓ Help parents to identify what is important to them and their child and plan goals for learning and participation.

Portage was not designed specifically for the parents of children with autism. Instead, the National Portage Association provides the module 'Complex Social Communication Difficulties / Autism Spectrum Disorders (ASD)' as one of the Portage Curriculum for Continuing Professional Development modules to accommodate parents of children with autism who are of pre-school age. Indeed, Portage worker trainees by the end of the module would be able to:

1. Examine the Portage model within the context of meeting the needs of children with autism.
2. Consider the relationship between the Portage model and recent developments in early interventions for children with social communication difficulties including autism.
3. Understand the needs and individual differences of children with autism.
4. Plan home visits considering recent knowledge in autism and develop appropriate methods of recording.

5. Develop strategies for enhancing the communication, play and learning of children with social communication difficulties including autism.<sup>32</sup>

#### 3.4.6.4 More than words: The Hanen Programme for Parents of Children with Autism Spectrum Disorders

The More Than Words Program was designed by expert speech-language pathologists. Five-year old children and under are the programme's target group. It is designed specifically for parents to help their children reach their full communication potential by providing them with the strategies, tools and support they need. The program focuses on utilizing the natural, day-to-day life to enhance the child's social skills, the language understanding and the skill in engaging in back and forth interactions. The programme is composed of eight small group training sessions, followed by three home consultation visits led by a speech-language pathologist<sup>33</sup>. Thus, similar to previous parental training programmes, little is published in regards to the programme's effectiveness. For example, in a study conducted by McConachie et al. (2005) to evaluate the *More than Words* programme, the result showed that the training has a measurable effect on both the parents' and the children's communication skills.

The following table (Table 7) summarizes previous parental training programmes in term of their philosophy, targeted group, components, duration, delivery approach and effectiveness. Based on the table's summaries, it could be concluded that the current provided parental training programmes share some common features in terms of delivery approaches and limited research evidence regarding the training effectiveness. However, they vary in their philosophies, duration, and components. Indeed,

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<sup>32</sup> <http://www.portage.org.uk/>

<sup>33</sup> <http://www.hanen.org/Hanen-Programs/Programs-For-Parents/More-Than-Words-Parent-Program.aspx>

these emphasise a lack of a clear framework to conduct and run such services and highlight the limitations in the literature regarding such parental programmes. Thus, this would suggest further investigation is recommended to sensitive service providers, as this would justify the current study's aim in trying to fill some of that gap.

Table 7 Current Parental Training Courses

Programme	Philosophy	Target group	Duration	Components	Delivery approach	Research evidence	Developer
Early Bird	<ul style="list-style-type: none"> <li>✓ Build parental confidence.</li> <li>✓ Addressing communication deficit in autism in relation to underlying triggers of difficult behaviours.</li> </ul>	parents of preschool children diagnosed with autism	Three months training programme	A diverse collection of best practice: <ol style="list-style-type: none"> <li>1. SPELL</li> <li>2. TEACCH</li> <li>3. PECS</li> </ol>	<ul style="list-style-type: none"> <li>✓ Group training sessions.</li> <li>✓ Individual home visit.</li> <li>✓ Video feedback.</li> </ul>	Limited study evaluated the training programme:	The National Autistic Society
The Son-Rise	<ul style="list-style-type: none"> <li>✓ Believing in child's ability.</li> <li>✓ Addressing the role of love and acceptance.</li> <li>✓ Considering parents as an important resource for a child.</li> </ul>	parents and professional of any age group	Five-day training programme	<ul style="list-style-type: none"> <li>✓ Speech and language development.</li> <li>✓ Behaviour management.</li> <li>✓ Enhancing motivation and empowerment.</li> </ul>	Slides./Videos./Lectures/Activities./Question and answer sessions. /Creating a playroom. /Manual of the key elements of <i>The Son-Rise Program</i> to refer to at home.	lack of research evidence	The Option Institute and the Autism Treatment Center of
The Portage	<ul style="list-style-type: none"> <li>✓ All children are able to learn.</li> <li>✓ Values the diversity.</li> <li>✓ Key role of Parents.</li> <li>✓ Importance of Early childhood.</li> <li>✓ Enhance quality of life and experience through every day activities.</li> </ul>	Preschool children with additional support needs and their families. Not specific to autism.	Not-specified	a) Supporting the development of play, communication, relationships, and learning for young children within the family. b) Helping parents to identify what is important to them and their child and plan goals for learning and participation.	Home-visiting educational services.	Establish effectiveness but lack studies that evaluate the training within the context of autism.	National Portage Association
More Than Words	<ul style="list-style-type: none"> <li>✓ Social interaction-intervention.</li> <li>✓ Families' involvement central.</li> <li>✓ Importance of the natural, day-to-day life.</li> </ul>	Parents of five - year old children with autism and under.	Minimum of 17.5 training hours in 8 sessions Followed by a three home visits.	<ul style="list-style-type: none"> <li>✓ Parent education.</li> <li>✓ Early communication intervention.</li> <li>✓ Social support for parents.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Groups training sessions.</li> <li>✓ Three home consultation visits.</li> <li>✓ Parent guidebook.</li> <li>✓ DVD.</li> <li>✓ PowerPoint slides with video examples.</li> </ul>	Little is published in regards to programme effectiveness	The Hanen Centre.

### **3.5 Conclusion**

Considering that the current study's aim is to develop a parental training programme that would lead to an early intervention home-based programme, the attention has been directed toward: first, general information regarding autism was provided as an introduction to this chapter. This is because autism deficit is core to the current study's investigation. Second, early intervention importance and implementation was examined within the context of both home-based intervention and parental training. Third, examples of existing parental training programmes that could provide a framework that could lead to an early intervention programme for individuals with autism, especially by acknowledging that there are a variety of interventions strategies that have been documented in the literature. However, the discussion concentrated only on strategies that could be applied in a home-setting, as this would exemplify the current study aim in developing a parental training programme and identifying its components based on both identified parental needs that have been obtained from current study data and available practice acknowledged in the literature.

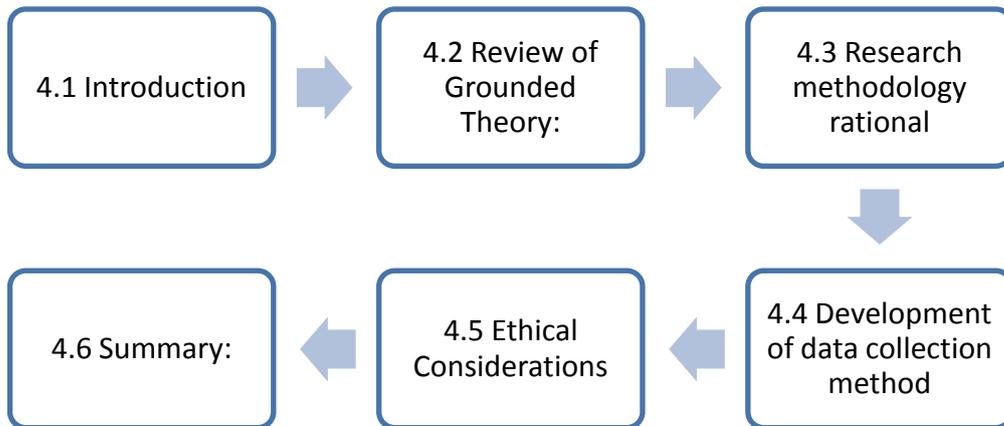
## **Chapter 4: Methodology**

### **4.1 Introduction**

The main aim of this research is to develop the parental training programme that emerges from the parents' needs in relation to their children with autism. The approach used is a constructivist grounded theory approach in order to identify the programme components, their implementation and their effectiveness. The research methodology and questions aim to provide the data that is the basis for formulating the theory concerning the dissertation. Several data collection techniques (interviews, questionnaires, evaluation sheets, parental stress index short form (PSI-SF)) were used to fulfil the research objectives and answer the research questions. The overall goal is to use the feedback provided by the parents to establish an effective, efficient program to help the parents administer some of the therapy that is needed on a day-to-day basis to their autistic children with the minimal amount of stress to the parental life style.

Indeed, in this chapter, the research paradigm used for this thesis is discussed as well as a brief overview of the grounded theory approach and how it applies to this research. There are many methods of data collection that are discussed in detail in this chapter taking into account the research question, as well as the considerations for any limitations that these methods may encompass. These various methods include interviews, questionnaires, evaluation sheets and PSI-SF. Finally, a review of triangulation is provided.

Figure 7 Structure of Chapter Four



## 4.2 Brief Review of Grounded Theory

Grounded theory (GT) is a method that analyses qualitative data using an inductive process to generate a theory or conceptual understanding based on data. In other words, grounded theory is an overall explicit strategy to develop theory grounded in the data; it is a theory generation approach (O'Donoghue, 2007; Punch, 2009; Chenitz, 1986). Strauss and Glaser (1968) collaboratively established grounded theory as a new approach of qualitative analysis in their book, *The Discovery of Grounded Theory*. The book was based on a valuable justification of using systematic qualitative procedures to develop theoretical analysis. Their efforts in developing such an approach have moved qualitative research forward from a descriptive framework to a more explicit, conceptual and theoretical framework (Goulding et al., 1999; Charmaz, 2006). The Strauss (1987) study considered the grounded theory framework as:

“a style of doing qualitative analysis that includes a number of distinct features, such as theoretical sampling, and certain methodological guidelines, such as the making of constant comparisons and the use of coding paradigm, to ensure conceptual development and density” (Strauss, 1987: p.5).

The use of the grounded theory has become increasingly popular in different academic domains since its discovery. Previous studies point out that there has been some debate over the two main existing approaches, the Glaserien and the Straussien grounded theory frameworks, as the founding fathers have taken grounded theory into two different directions. On one hand, the Glaser (1999) study seems to favour the classical earlier method in which data is a fundamental part of the approach where data should be analysed inductively through a clear framework of stages to generate new knowledge rather than adding to existing ones. This systematic procedure is composed of two phases: substantive coding and theoretical coding.

Substantive coding consists of open coding and selective coding. Open coding is the ‘initial stage’ where no preconceived conceptions exist and researchers are open to what the data might reveal. This step would lead to the emergence of selective coding from core coding, whereas the theoretical coding phase emerges from the relationship between the coding categories, which leads to theory generations (Glaser, 1968). The Glaserien approach emphasises that grounded theory is a method of discovery.

On the other hand, the Strauss and Corbin (1998) study emphasised the extremely structured coding paradigm. The data analysis process includes three phases; open coding, axial coding and selective coding. Open coding and selective coding are comparable to Glaser’s framework of open coding and theoretical coding respectively; the difference being that the axial coding used in the Straussien method consists of a set of deductive and inductive complex processes that aim to make a connection between the categories by making comparisons and asking questions. This technical process is accomplished by developing a coding paradigm involving conditions, context, actions/interactional strategies and consequences (Strauss and Corbin, 1998; Strauss and Corbin, 2008). In other words, the axial coding of the Straussien method is used as part of the coding paradigm rather than emphasising on the comparative methods, as in the Glaserien method. According to Corbin and Strauss (2008) verification is an essential part of grounded theory. Despite some commonalities that exist between

the two grounded theory methods, there are many differences between the Glaserian and the Straussien methods and criticisms which have been detailed in grounded theory literature.

Since then, other theorists (Heath and Cowley, 2004; Charmaz, 2006; and Creswell et al., 2007) have made some contributions to the grounded theory framework. The Heath and Cowley (2004) study focused on the cognitive styles of research. Their perspective is based on their belief that “qualitative analysis is a cognitive process and each researcher has a different cognitive style” (Heath and Cowley, 2004: p.149). The Charmaz (2006) study proposed that basic grounded theory guidelines such as coding, memo-writing, theory-sampling and comparative process could be used by researchers to conduct their research. An in depth look into the Charmaz framework is examined in the next section in order to understand the context of how these tools for research are used in the grounded theory framework.

#### **4.2.1 The Charmaz Framework**

According to the Charmaz perspective, grounded theory is essentially a set of principles and practices, and not perceptions or packages that emphasise the examining processes, constructing action as central to the study and developing an abstract understanding of the data (Charmaz, 2006). However, one point of contention between the Charmaz perspective and those of other grounded theory perspectives is that the Charmaz perspective implies that the theory of the research should be based on past experiences and present involvement with the research data and scientific observation. This is based on the statement, "neither data nor theories are discovered", (Charmaz, 2006: p.10). Based on this premise, the concept of having no pre-notion is not beneficial. Indeed, Charmaz emphasises the role of both the participants' and the researchers' feelings, views, beliefs and values on the process of theory development (Creswell, 2009; Charmaz, 2006). According to the Charmaz perspective, theoretical reproduction is not an exact picture of the studied phenomena, instead it provides an interpretive representation of it (Charmaz, 1995b). The Charmaz constructivist

approach encourages research to theorize in interpretive traditional methods. Charmaz (2006) views interpretive theory as follows:

"Interpretive theory calls for the imaginative understanding of the studied phenomenon. This type of theory assumes emergent, multiple realities; indeterminacy; facts and values as linked; truth as provisional; and social life as processual." (Charmaz, 2006: p.126).

The Charmaz framework appears to be flexible in structure and reflexive. According to Charmaz, due to the fact that the research process is not linear, the grounded theory's final thoughts are suggestive, incomplete and inconclusive because it fails to give the researcher the flexibility to develop his/her thoughts whenever new ideas emerge, as some brilliant ideas may arise later in the process (Charmaz, 2006). Therefore the aim is to develop a deep understanding and interpretation of the phenomena that have been under investigation, rather than discovery (Heath and Cowley, 2004).

#### **4.2.2 Grounded theory, nature and limitations**

As discussed earlier, the grounded theory approach is part of the qualitative framework 'family', where almost all research approaches are grounded in the data to a certain extent. Indeed, the openness, flexibility and the clear and precise guidelines provided by the grounded theory approach on how a researcher might proceed in doing his/her project, add an additional advantage to such frameworks (Charmaz, 2006). The GT framework guidelines that have been specifically proposed by Charmaz are summarized in the following paragraph, along with some general illustrations of some strengths and weaknesses of the GT approach.

The process of conducting a grounded theory project commences by focusing on a specific area of interest then addressing the gap in knowledge. Indeed, identifying the research problem is fundamental within the grounded theory approach. Therefore, researchers are advised to consider the following issue when choosing their research problem; research problems that have limited empirical-based literature are more applicable for following the GT approach, as

this gives the research a broad area to investigate and generate new knowledge. In contrast, the widely investigated area that has empirical-based literature would be more problematic, because the researcher might be in danger of repeating existing knowledge rather than developing a new insight into the investigated phenomena (Goulding et al., 1999).

Examining the literature related to current dilemmas pertaining to the investigation of parental needs in relation to their autistic children identified that research in this area is limited. One reason for this limitation is, in part, that most studies do not take into account the parental perspective in the various types of services offered to autistic children. Therefore, in order to abridge the lack of knowledge in the field, this study utilises constricting GT to develop an insight on the study population's need. Despite support for the Charmaz argument, the concept of using a method that has no pre-notion is not beneficial for this study. This study utilises the researcher's background knowledge on the subject to facilitate the research process, especially in situations that are so sensitive. Almost all researchers would be influenced by their background, which would lead them to a specific problem to investigate. Goulding et al., (1999) stated that the researcher's background brings more focus and sensitivity when gathered data is being analysed and interpreted.

Although determining the research problem is essential, data collection is one of the most pivotal steps in research. According to Creswell (2003), data collection is the stage which includes setting the research boundaries. This research follows the examples of Bell(2010) and Creswell (2009), which identified that boundaries are not limited to the standard boundaries of typical research in this field, but also to cultural boundaries and sensitivities that demand more than one method in order to obtain the data and feedback. According to Charmaz (2006) "the quality and creditability of study start with data" (p, 18). Therefore, the data collection stage is essential to gather rich data, as concrete information would help in building a significant analysis. In the GT approach, data gathering is an ongoing process where the researcher has the flexibility to add and modify ideas, even late in the analysis. Glaser (1999) argues that theory could be generated through

comparisons, regardless of the quality of the data, as he states, 'all data' (p.841). Charmaz agrees with Glaser's viewpoint and states that everything the researchers learn about the research topic and through the research settings could be regarded as data. Bell (2010) states that research approaches usually depend on more than one method. Such methods are regarded as a researcher's data collection instruments which enable him or her to fulfil the research objectives and answer the research questions. GT methodology depends on different types of data collection methods that the researcher might invoke upon various methods in order to gather data. This might include interviews, observations, focus groups, field-notes and audiovisual materials (Creswell, 2003; Charmaz, 2006). The various data collecting techniques are discussed in further detail later in this chapter.

The GT approach is centred on the data interpretation or data analysis. The research procedures are outlined based on what theory has been generated. The systematic guiding principles for analysing processes, involving coding, memo-writing, and theoretical samplings, are distinct features of GT methodology.

Coding in grounded theory is an active interrelated process where the researcher takes an action upon the data, rather than receiving them passively (Charmaz, 2006). This process occurs in two phases: open-coding and focused-coding. Open coding is the initial stage when the researcher starts to explore the gathered data closely and openly, line-by-line, in an attempt to begin conceptualising the emerged ideas. Charmaz (2006) indicates that fitness and relevancy are two criteria for completing a grounded theory that is achieved through this initial coding stage. The focused coding process is associated with sorting and combining a large amount of data through constant comparison of similarities and differences between emerging codes in order to develop themes. This phase is very critical because it is more focused and selective compared to the open coding stage.

Memo-writing is another key feature of the GT approach. Data interpretation starts at the early stages, once the researcher starts gathering data. In addition, GT

data gathering and interpretation goes hand in hand. The research has the flexibility to reshape the data collection methods at the same time that the data is being collected and observations are being recorded. This GT approach is called 'memo-writing'. Although researchers have the flexibility to move between stages of their work, following systematic procedures consolidates the final work. According to Charmaz (2006), coding is defined as:

“categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data, codes show how research select, separate and sort data begin an analytical accounting of them”, (Charmaz, 2006, p.43).

In other words, it is the note-taking process by the researcher throughout and after the data collection and whilst conducting the coding process. Memo-writing encourages researchers to start coding and analysing procedures at an early stage of their work (Charmaz, 2006). Goulding and colleagues (1999) say memos provide 'a bank of ideas' that facilitates the researcher by allowing them to incorporating and merge ideas.

The two previous GT protocols lead to theoretical sampling which is another major criterion of GT. Theoretical sampling is a systematic comparative process for discovering gaps within the data and categories with the aim of filling that gap by gathering specific data to refine the key research categories. Theoretical sampling is a tool that researchers use to enhance analysis, clarify relationships between ideas and ensure that categories have been fully constructed. Indeed, the process of constantly comparing categories and data in theoretical sampling promotes a high level of conceptualization. Due to the emergent process involved, sampling becomes saturated, which is a goal of GT. Saturation is the stage when the data no longer directs the researcher to new categories and deep insights (Charmaz, 2006). At the stage of theoretical categories saturation, the theorising portion begins.

Previous illustrations of GT key elements and mechanisms emphasise the importance of constant comparative processes in all of the analysis stages.

However, classifying these analytical stages does not imply the process is linear, due to the flexible nature of the study in which the researcher has the flexibility to move around and generate ideas and new insights when needed. Thus, classifying those phases aims to describe the systematic framework that the researcher used to obtain the theory. A detailed description of the current study's analytical framework is discussed in detail later in this chapter.

Similar to any methodological approaches, GT methodology has strengths and weaknesses. Here, some of the strengths and weaknesses that have been discussed within the literature are detailed. Systematisation, flexibility, openness, constant comparison, conceptualisation and inductivity, as highlighted in the previous paragraphs, are the most acknowledged grounded theory strengths. Other strengths include the inexpensiveness of data collection, the richness in the meaning and the fact that all kinds of data could be used (Glaser, 1999). In contrast, the GT approach has also have been criticised in the literature for many reasons. These criticisms draw attention to some weaknesses within the approach. For example, there are different versions of GT which might confuse researchers with their framework and procedures (Goulding et al., 1999; Coyne and Cowley, 2006). Another controversial issue about the GT approach is the risk of misusing the GT analytical framework, so that the data being described may not be conceptualized (Goulding et al., 1999). Theory generalisation is another problematic topic within the GT debate as researchers ought to be cautious about generalising from small-scale projects and short studies (Goulding et al., 1999).

Other weaknesses are mostly related to the Glaser framework or the Strauss framework. For example, the Glaserien idea of not consulting the existing literature for the area under study has been criticised. This is because the researcher's aim is usually to build new knowledge on the existing. Therefore, the researcher might be in danger of 'reinventing the wheel' (Goldkuhl and Cronholm, 2010: p.191). The Straussien method has been criticised because of the usage of axial coding. One critic against axial coding was Glaser (1992) who viewed axial coding as more of a process in which data is forced to shape a theory rather than letting theory emerge from the data.

### 4.3 Research Methodology Rationale

There are several reasons that justify grounded theory as the most relevant for addressing the current study problem. First, its relevance in educational research emerges from the necessities that became apparent from identifying and examining the research problem within its contexts. Consequently, professional practices and policies were developed. Goulding et al., (1999) argued that grounded theory “was developed for, and is particularly suited to, the study of behaviour” (p.18). Thus, test or verified theories may not be as explicit for and sensitive to human problems as a qualitative approach, such as grounded theory. This is because conducting grounded theory approaches gives research the privilege of being exploratory, sensitive, flexible and yet systematic when examining particular human experiences within its natural setting (Punch, 2009; Chenitz & Swanson, 1986). This is the case for this study, which focuses on the examination of the parents’ needs in relation to their children with autism and comprises difficult human experiences that are explored and reflected upon.

Secondly, in light of this research, these are the main questions and research sub-questions being investigated:

*How should a parental early intervention training programme be developed in the light of parental understanding of the nature of autism and the parental role in the child’s development within the Saudi context?*

- ✓ How might a parental training programme be developed?
- ✓ What should the programme components comprise?
- ✓ How might a parental training programme be run?
- ✓ What intervention strategies would be more effective and suitable to implement for an age group of between two and six years?
- ✓ How could programme effectiveness be evaluated?

The “how” and “what” type of questions are well suited for the qualitative approach as both types of question give the sense of being exploratory and of reflexivity (Creswell, 2009; Strauss, 1990). The approach for the current study focuses more on meanings and understandings in natural situations (Silverman,

2004). Therefore, constrictive qualitative grounded theory was decided to be the best approach for this study. Indeed, this qualitative approach is a flexible systematic procedure which follows an interpretive way of thinking which gives the researcher the opportunity to understand how others understand their world and use the acquired understanding to improve the quality of human life (O'Donoghue, 2007). Researchers are the primary instruments for data collection which gives leeway to reflect upon the sensitivities concerning the method of collecting and analysing data as well as the overall shaping of the study's findings (Creswell, 2009; Ary et al., 1990).

Third, the lack of theories that explain participants' behaviours and complicity in identifying variables that affect participants' behaviour, make the qualitative ground theory methodology befit the situation at hand, due to the fact that there is a limited theoretical base (Creswell, 2007). This is because a parent's response towards having a child with autism is determined by their understanding and interpretation of the event. Therefore, investigating and understanding the parent's experiences, feelings and actions regarding having a child with autism is relatively important in order to be able to develop a theory that will explain the parents' needs in relation to their children with autism, taking into account the Saudi cultural sensitivities mentioned in the chapter on Saudi. Indeed, most previous studies that have been conducted within the Saudi context relied primarily on quantitative methods (e.g. Alghanim, 2005; Albeheiri, 2004). Minimal considerations were given to examine parents' experiences, actions and feelings. Therefore, this methodology offers the opportunity to develop a conceptual framework in regard to the experiences of the study population. Strauss and Corbin (1998) stated that when a theory is not available to explain how people experience phenomena, grounded theory is a best framework to use.

#### **4.3.1 Research design**

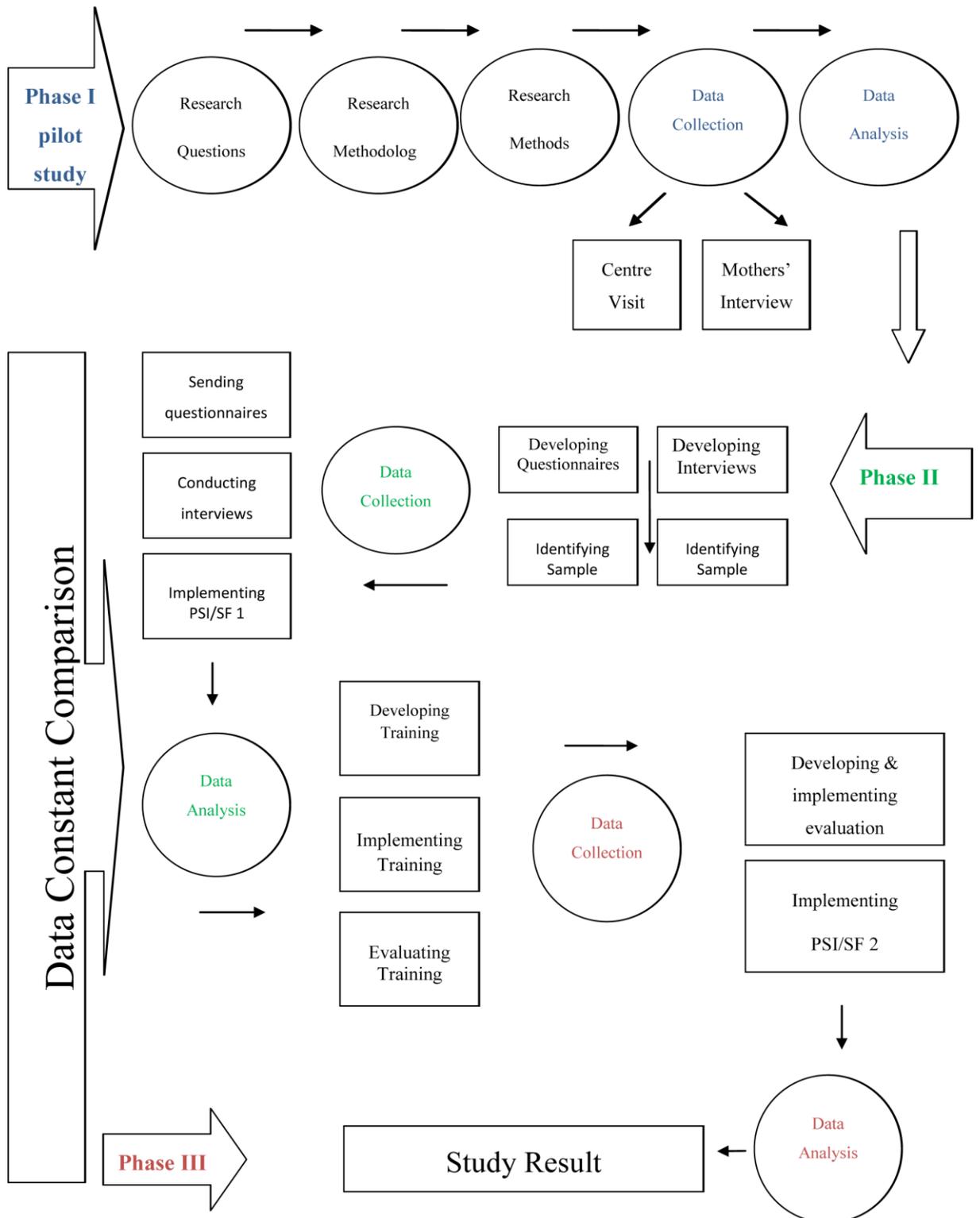
As mentioned earlier, the current research adopts the Constructive Grounded Theory methodology. Therefore, the process of adopting such a framework involves; first, determining the area of interest and identifying the research questions, whilst considering that the researcher's previous knowledge and

experiences will influence this stage. The following illustration is quoted from the research memos. “Being a special education teacher, I came to the field occupied with the idea that children with autism should be helped to develop to their maximum ability, believing that the parental role is crucial in child development. My image was that a parent’s ability to help their children effectively is affected by two factors: the parents’ limited knowledge about the autism nature and its resultant problem on their child development along with parents’ lack of effective educational intervention strategies that might facilitate child rearing. My view was parents need to be trained.”

However, this image was developed and subsequently changed through the involvement within the research process. As knowledge and intervention strategies were initially thought to be the main parental needs, throughout the research, not only were other needs identified but the research had to reconsider these other needs and go beyond them.

Indeed, examining existing literature on studies regarding parent training programmes’ structure and components, along with effective intervention approaches techniques helped in identifying the research questions and some ideas that could be incorporated in order to develop a parental training programme. Some may criticise this step, claiming that examining previous literature could potentially affect the development of a new theory. However, adopting the Charmaz approach has afforded me the privilege of doing so, as the aim here is to build knowledge on the existing knowledge in the specific context of the ‘Saudi culture’ by considering people’s experiences, actions and feelings. Goldkuhl et al., (2010) argue that existing theory should not be ignored by researchers because it is important to relate to the current established theories. The following chart (Figure 8) summarises the steps that have been undertaken in order to conduct this study.

Figure 8 Methodology Process



The previous research design steps led to the pilot study (see Figure 8, Phase 1) that attempted to collect evidence related to early intervention programmes for individuals with autism in Saudi Arabia. The amount, depth and extent of the information collected takes into account the reality that such services are in the early stages of development in Saudi Arabia, due to the current limited experience in the autism domain generally and in early intervention programmes specifically. As such, this pilot study was intended to act as a basis for gaining a greater understanding about how such services could be developed in Saudi Arabia in the future.

The first step was to visit a publicly funded autism centre in Jeddah and arranging to conduct pilot interviews, not only with parents whose children are either currently receiving the provision of services, but also with parents whose children are on the waiting list for a place within the centre. These arrangements were made subsequent to the development of the interview questions for these parents in order to seek their experiences of the current intervention and support services that are available. However, the interview questions and the findings have directed the researcher towards more specific data that needs to be collected, whereby the researcher decided to collect information from a general sample and a specific sample. The large general sample involved parents of children from different age group. A questionnaire was developed in order to cover this large population with the aim of enquiring about their experiences. The specific sample comprised the population that subsequently became the research interview sample and the participants within the training programme. The interview sample criteria are discussed in detail in a separate section within this chapter. According to Charmaz (2006), this step reflects the initial sampling stage, where the pilot interview directed the research towards identifying what information needed to be acquired and from whom.

After these arrangements had been made, a visit to another new publicly funded centre, which was established eight months prior to the pilot study being conducted in Jeddah. The centre aims to offer early diagnosis and early

intervention for individuals with different disabilities including autism. The aim of this visit was to gather evidence about how this facility was currently operating in practice. As a result of this visit, it was evident that the organisation has not yet established any specific intervention programmes for individuals with autism. This appears to be due to the fact that the service is relatively new and has a shortage of qualified teachers to deal with individuals with autism. However, the head teacher stated that she is happy to co-operate and accommodate such programmes within the centre.

After visiting one of the well-recognised private centres in Jeddah that offer early intervention programmes for Down's syndrome individuals, an interview with the head of the early intervention unit was conducted. The interview focused on programme objectives; programme implementation; specific intervention approaches and the methods that the centre use. A brief report about the programme is given in Appendix (A), as an example of successful early intervention programmes in Saudi Arabia.

Furthermore, a workshop designed for families on the principles and practices of developing home intervention programmes for individuals with autism was attended in order to gather data. The workshop highlighted the importance of developing such programmes in Saudi Arabia, in which practical examples of recommended programme components and implementation strategies were given. In the second part of the workshop, participants were then encouraged to apply the skills that been discussed in practice with their own child.

Whereas the previous interviews and visits could be seen as a diagnostic step, not only to establish the feasibility of undertaking research in this specific domain, but also to highlight the many important issues that directed the researcher's steps towards conducting this study; the following provides an outline of some of these steps that were undertaken following the pilot study. Step one was to determine a research sample. Step two was gaining permission from the various organisations and governmental facilities to conduct the research and to have access to the current data. Step three was to develop the data collection methods, including the

questionnaires and the interview schedules for conducting the practical part of this study.

#### **4.3.2 Research sample**

Two categories of participants, being parents currently receiving intervention centre-based services via autism centres, were represented in the research sample; the first category was an open sample based on a larger, more diverse, and more representative sample from the target group. To target the open sample two hundred questionnaires were sent to the parents. The purpose of recruiting this open sample is to identify the parents' common and ongoing needs from the diagnosis stage to the most recent time, regardless of the child's age, gender, and autism severity level. In contrast, a selected sample was planned, which is smaller and should meet the specific inclusion criteria. These criteria include novice parents to autism, with a newly diagnosed child aged between two and six years with a severity level from mild to moderate, who are not currently in any program. Twenty mothers were recruited to be interviewed and asked to participate in the training programme. Only twelve were able to attend the training programme, with only eight of them able to complete it. A detailed discussion of recruiting and maintaining the research sample is highlighted in the following paragraphs.

#### **4.3.3 Gaining the permission process**

Keeping in mind that the culture that is being examined and referenced is the Saudi culture, as well as that the area is being examined in the cultural context, is considered to be highly sensitive, obtaining information that may be seen as normal in most cultures around the world has been met with some resistance to divulge information, and is usually considered to be very private in Saudi Arabia. Consequently, preliminary steps had to be taken prior to collecting the data in order to necessitate the research process for this study. One such measure was to obtain permission from the Saudi Ministry of Education in order to be able to access schools and centres where educational provision is provided for individuals with autism. The nature of the fieldwork being conducted is limited

due to the highly protective nature of centres and organisations that deal with any autism services for children with ASDs in order to protect the confidentiality of the families. Thus, securing permission to obtain the information and access to some of the families was detrimental to this study. Even so, finding families willing to divulge personal information demanded a high-level of sensitivity and trust that the information would remain anonymous.

Following that, two organisations that provide services for individuals with autism were contacted in order to obtain an agreement to host the project and to facilitate the researcher by offering the use of their location in order to conduct the interviews and the training course. Fortunately, both organisations were obliging. However, in order for the programme to work, a facility had to be found that could accommodate various schedules and timings. One of these organisations was considered to be more preferable due to the available timings (both morning and evening working hours) and the availability throughout the year as the private organisation does not have to observe the public holidays, thereby making it more accessible to the families and the research flexibility to arrange the interviews either in the morning or the evening based on the mothers' time preference.

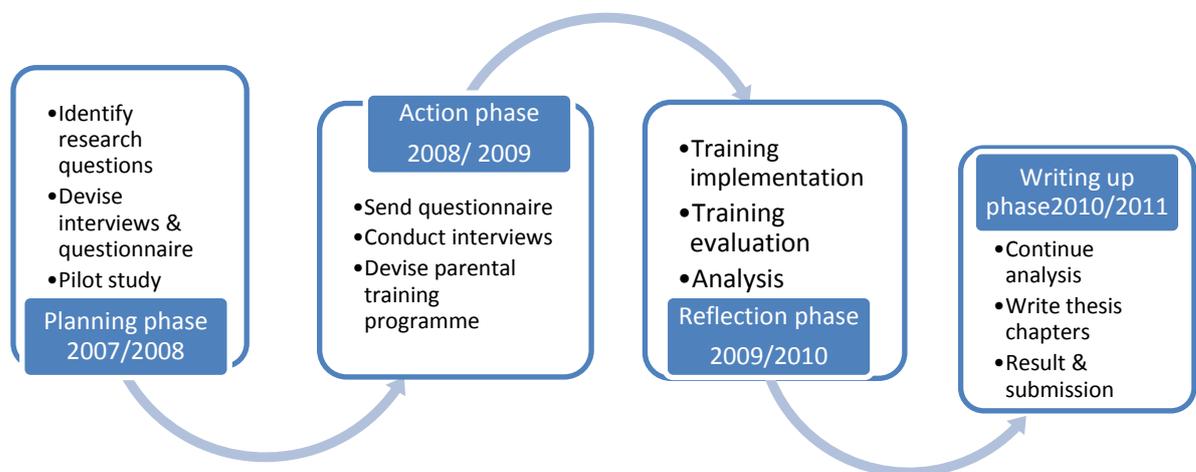
Following the gaining of permissions from the clinics and organisations that provide diagnostic services, thirty-six families that met the recruiting criteria were contacted via telephone. However, recruiting and arranging with the mothers to be interviewed was not an easy task, and this process took five months (starting from mid-November 2009 to mid-March 2010).

#### **4.4 Development of the Data Collection Method**

The data collection method comprised of four methods: interviews, questionnaires, Parent Stress index short form and an evaluation form. This method of using more than one method approach is known as 'triangulation' (Robson, 2002; Silverman, 2010). 'Triangulation' is an important part of the process of data collection and analysis because it helps in corroborating and examining evidence from the data, and subsequently uses it to build a coherent,

strong structure for the research. In addition, the triangulation of different data sources increases the research validity and reliability by having a cumulative view of data drawn from different contexts (Robson, 2002; Creswell, 2003). Moreover, triangulation helps to limit bias and disadvantages that might be associated with different types of data collection methods (Robson, 2002). Based on this information, a triangulation approach will be used for this study. Figure (9) summarises the data collection timeline, and the four main methods used within this study are discussed below in further detail.

Figure 9 Timeline of Data Collection



#### 4.4.1 Development of the questionnaire

Questionnaires are one type of data collection method that is used in qualitative approaches. Questionnaires are a good tool for collecting certain types of information quickly and relatively cheaply (Bell, 2010). It is proposed that self-completion open-ended questionnaires will be used to examine the experiences of the parents of individuals with autism, both before and after seeking the autism diagnosis, the parent’s ability in identifying their child’s difficulties, the parent’s perspective of their family role in relation to the child, and support that the family and child receive. These questionnaires were sent out with the purpose of collecting information about parental training related issues, which might help in developing such training and also in identifying barriers that might face developing and implementing such services in Saudi Arabia. Furthermore, the responses are important in order to know how these issues are perceived from these perspectives.

Questionnaires, however, as a method of data collection have both advantages and disadvantages. Robson (2002) summarises the advantages of questionnaires as follows: questionnaires are the only way of retrieving information from a large set of people, questionnaires are considerably more efficient in both time and money costs, and it is easy to resend them back to research participants if required. The limitations of this technique that were mentioned are that the sample may be not representative, participants may misunderstand the questionnaires or their answers might be ambiguous, or respondents may ask for help to answer questions so the responses might not represent their knowledge, experience and personalities.

Within this study, the questionnaires were developed for parents who have children with autism. The construction of the questionnaires required special consideration given the fact that the recipients vary in terms of their demographics. Consequently, the research takes into account the participants' educational level, which might affect their understanding of and response to the questions. Thus, this can be seen as one of the disadvantages of the questionnaire approach in this study. In particular, the questionnaire was constructed to be clear and precise, avoid complex and potentially ambiguous questions by keeping the language level simple, and by making sure that the questions reflected the aims of the research. Another consideration was the length of the questionnaire which was specifically designed to be not very long. The questionnaires were devised first in English and then translated into Arabic. The questions were devised to cover demographics information, the parents' knowledge about autism, parental awareness of their role in their child's situation, parental knowledge about therapy, obstacles facing both parents and children. The parents were asked to answer twenty-one questions plus thirteen statements that were ranked on a scale of five, from strongly agree to strongly disagree. The questionnaires were revised whenever needed, and as agreed by the research advisers who are specialists in the field of autism, and the researcher. After translating the questionnaires into Arabic, two special education teachers (one of whom is the mother of a child with autism), psychologists and an Arabic language editor were consulted and engaged

in the process of revising the formulation of the questions, with the purpose of ensuring that all of the questions were relevant, accessible, precise and clear. Consulting all of the specialists was felt to be essential to help in the piloting of the questionnaire schedules and to consider the questions' reliability. (See Appendix (B) for more information regarding the questionnaire questions).

A total of seven hundred and twenty copies of the questionnaire were physically sent to participants that had cases registered within the schools and centres in three Saudi cities: Jeddah, Riyadh and Makkah. Each copy was forwarded with a letter requesting clients to complete the questionnaires. The cover letter emphasised the purpose of the research, the importance of the parents' responses and that the outcomes would be used for research purposes only. More importantly, the cover letter was headed with a narration of the Prophet Mohammed, indicating that answering the questionnaires would be regarded as beneficial to knowledge that is not only physically rewarding but also spiritually rewarding. Indeed, providing such a narration supports the research theoretical perspectives that emerge from the Islamic perspective, in that this approach might shape people's thinking in Saudi Arabia. The parents' responses were sent to the schools and centres, from where they were physically collected. In addition to this, the questionnaire was launched online via the centres and autism societies' websites.

The sending and collection of the questionnaires took about four months in total. The first batch of surveys totalled about 400. Both Arabic and English copies of the surveys were sent to and physically collected from the schools and autism centres. The number of copies returned was 65, whereas 200 copies was the target number. Due to the low number of respondents, 432 questionnaires were resent to the schools and autism centres. In addition, the questionnaire was launched online and broadcast via the centres, schools and a specialised website within the disability field in order to target more people. Despite this effort, the final number of useable copies was 251. The following table (8) illustrates the questionnaire's timeline.

Table 8 Questionnaires Timeline

	Centre Name	No Of cases	Sent copies	Sending Date	Received copies	Receiving Date	City
1	Public autism centre	58	65 + 52	11/10/09 09/12/09	15+ 19	15/11/09 19/12/09	JED
2	Saudi autistic society	-	20	11/10/09	8	14/11/09	JED
3	Pffac	30	30	11/10/09	19	20/12/09	RYD
4	Ethar centre	25	25	01/11/09	6	26/12/09	JED
5	Alkemmah centre	16	16	01/11/09	10	17/11/09	JED
6	Al raiah w alhanan	9	9	01/11/09	0	26/12/09	JED
7	Autism centre	30	40	02/11/09	13	26/12/09	JED
8	Saudi autism centre	6	10	02/11/09	5	19/12/09	JED
9	First step centre	10	10	02/11/09	3	17/11/09	JED
10	Rawdah Alanjal	4	4	02/11/09	3	17/11/09	JED
11	Azam centre	20	20	03/11/09	11	20/12/09	RYD
12	Jish centre	30	20 AR- 10EN	09/11/09	4en/1ar	28/12/09	JED
13	Basmah centre	5	5	09/11/09	3	26/12/09	JED
14	Special education academe	80	80	09/11/09	32	20/12/09	RYD
15	Alamal Al manshod centre	45	45	10/11/09	34	04/01/10	Mkh
16	Almaaweeh	16	16	10/11/09	0	27/12/09	RYD
17	Alola School	15	15	10/11/09	10	8/12/09	JED
18	Early intervention centre	3	3	10/11/09	2	9/12/09	JED
19	Amal Jeddah for rehabilitation	10	10	10/11/09	10	8/12/09	JED
20	Social force hospital (diagnostic center)	-	15	14/11/09	6	30/12/09	JED
21	Hope centre	11	10 AR-1 EN	15/11/09	4E/1AR	19/12/09	JED
22	Nourah centre	6	6	15/11/09	4	19/12/09	JED
23	Tawasl centre	1	1		1	18/11/09	JED
24	Alraiah Almutaturah centre	8	0 refuse to take the questionnaire				JED
25	Happy childhood centre	4	No return				JED
26	Afkar Alsegar	7	7	9/12/09	1	28/12/09	JED
27	Saakoon centre	12	12	9/12/09	0	26/12/09	JED
28	Badegish centre	8	8	9/12/09	5	26/12/09	JED
29	Tafelly Almotamies	10	10	9/12/09	6	19/12/09	JED
30	Boys autism centre	90	90	12/12/09	15	15/12/09	JED
31	JAccop		25	12/12/09	0	28/12/09	JED
32	Erfan Hospital (diagnostic centre)	-	25	13/12/09			JED
33	KFSH (diagnostic centre)	-	20	19/12/09			JED
34	Jeddah for special needs	12	12	04/01/10			JED
<b>Total</b>		550	732		251		

JED= Jeddah, Mkh= Makkah, RYD= Riyadh

Two hundred and seventy two parents responded and returned their questionnaires. Of these, twenty-one surveys were discarded. Analysis of the information from some of the parents' responses was difficult because some of the questions were either not answered or were incomplete, and in some cases the handwriting of the parents was illegible. Indeed, one can anticipate that if these twenty-one parents (who did return the questionnaires that were not used) had offered something in their responses, the total findings might have provided a different insight. Other factors that might be considered in relation to the possibility of response bias is that the questionnaire sample cannot be regarded as a representative sample or as a significantly different sample from the families of autistic children across the kingdom. Therefore, at this point it is worth acknowledging that this is an inherent limitation of using this method as a research tool. The results nevertheless are sufficiently robust to provide good indicative outcomes. The responses were coded and analysed and then compared in the light of the other data obtained from both the pilot study and some of the ongoing interviews that were conducting at that time. This stage of open coding helped to direct the data obtaining process towards identifying parental training components. Interpretations and findings are discussed in further detail within the next chapter.

#### **4.4.2 Creating the interview schedules**

Interviewing was used as another data collection method in this study. This tool can be defined as a meeting between the interviewer and the interviewee with the purpose of obtaining information from the interviewee (Bell, 1999). The study's key participants (20 mothers of children with autism) were interviewed.

In order to accomplish successful interviews a number of conditions need to be considered. Firstly, interviewing is a skill which requires an interviewer to be fully prepared, to be patient, and to ask clear and targeted questions. The type of interview needs to be selected; there are different types of interview and it is important to select the type which suits the research goals (Robson, 2002). The next consideration is the design of the research questions, and these should be based on the stated research objectives. Finally, the interview schedule needs to be piloted on a small sample in order to ensure its authenticity and also to check

that the questions do indeed cover the key research questions and that these are understandable and related to the research questions and aim.<sup>34</sup>

Within this study semi-structured open-ended interview questions were designed and used as an instrument of data collection. This type of interview falls somewhere between structured and unstructured interviews. Robson (2002) argues that it is the degree of structure of the interview that is the main difference between structured and semi-structured interviews. He argues that the semi-structured interview 'has predetermined questions, but the order can be modified based upon the interviewer's perception of what seems most appropriate' (p.270). This style of interview has many advantages as it allows the interviewees to respond freely to the interview questions and it also allows breadth and insight to the feelings and attitudes of the interviewees. In addition, it enables the interviewer to structure the questions to ensure that the crucial research issues are covered (Bell, 1999). Semi-structured interviews are flexible and give the interviewer a chance to ask supplementary questions of interest that emerge from the natural situation (Robson, 2002). Thus, the plasticity aspects of semi-structured interviews and its flexibility nature make it more applicable to fit the current research objectives of exploring and understanding the personal experiences of mothers having a child with autism. This is because semi-structured interviews provide both the interviewer and the interviewee with the flexibility to exchange concerns and ideas freely, where the researcher seeks clarification when needed. In contrast, the interviewees also have space to express their feelings and experiences freely.

However, conducting an interview is not an easy task and has many potential disadvantages. Most obviously, interviews are time consuming and therefore, time management is of the utmost importance. In order to determine a suitable interview time and duration, an estimation of the travelling time must be

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<sup>34</sup> Clearly, my position here regarding the aspects of the data that are concerned with the research in the aspect of validity, could be an issue in the measurement of the research, for which I use the term authenticity, reflecting the focus on concern in the interview situation to facilitate the expression of the subject voice.

included in the calculations along with extra time for any unexpected situations (Robson, 2002; Bell, 1999). Moreover, the interviews were recorded and in some cases accurately transcribed in order to avoid bias. Bias, which is an unfair opinion or emphasis, is another disadvantage of the interview method (Bell, 1999; Creswell, 2003).

Within this research, the interviews with the mothers who have a child newly diagnosed with autism in the age range of between two and six years old were taped. Subsequently the interviews were transcribed. Interview objectivity was maintained by following a clear and organised system in an effort to minimise the danger of bias. The following paragraphs discuss the advantages and disadvantages of the practical application of the interviewing process within this study.

A semi-structured interview schedule was developed for the mothers. Twenty questions were devised covering technical or practical information. Interview questions were generated from information gained from the literature review, the research aim and questions, and previous pilot interviews. Thus, agreeing on the right questions was not an easy task; this task took three weeks to complete during which time the final draft of the questions was compiled. This process involved constructing the questions, followed by revising and modifying them during several meetings between the researcher and the research advisers. Then, the interview questions were translated into Arabic. The precise formulation of the questions was discussed and revised by the researcher, two special education teachers (one of whom is a mother of a child with autism), psychologists and an Arabic language editor with the purpose of making sure that all of the questions were relevant, accessible, and precise and clear for all interviewees. It was essential to consult all of these professionals in order to help with the piloting of the interview schedules and to consider the questions for reliability. However, the piloting interview schedules proved to not be possible in practice, due to the time limitation and the small number of mothers who were to be interviewed.

The interviews questions concerned the following: firstly, the mother's experiences of suspecting that the child might have a problem and getting their child diagnosed. Secondly, the mother's actions and feelings towards the child's difficulties was another concern. Thirdly, the mother's view regarding both current and future services were also explored. A constant comparison in order to identify similarities and differences across the clients' responses was conducted to generate codes and cluster them into themes. A detailed analysis and an illustration of these codes will be discussed within the analysis chapter (see Appendix C) for further information regarding the interview scheduled questions).

Table 9 Interviews Timeline

Key: T - interview transcript translated from Arabic to English

Interview	Date conducted	Time	Duration
1	18/11/09 T	11:00 12:00 AM	00:38:05
2	23/01/10 T	06:00 07:00 PM	01:02:08
3	25/01/10 T	10:00 11:00 PM	01:07:28
4	30/01/10	08:30 10:00 AM	01:16:02
5	31/01/10	06:00 07:15 PM	01:11:27
6	01/02/10	09:30 10:45 AM	01:10:34
7	21/02/10	09:00 10:00 AM	00:53:47
8	22/02/10	05:00 06:20 PM	01:17:32
9	24/02/10	09:00 09:35 AM	00:35:00
10	24/02/10	06:30 07:00 PM	00:25:00

Table 10 timeline to be continued

Interview	Date conducted	Time	Duration
11	27/02/10	10:00 12:00 AM	01:48:24
12	27/02/10	06:00 07:00 PM	00:47:48
13	28/02/10	09:00 10:15 AM	01:14:09
14	28/02/10	06:00 07:02 PM	01:00:28
15	01/03/10 T	06:00 07:00 PM	01:00:50
16	02/03/10 T	09:00 09:40 AM	00:32:20
17	03/03/10	09:00 10:20 AM	01:18:50
18	03/03/10	05:00 05:50 PM	00:46:18
19	09/03/10	10:00 10:40 AM	00:39:49
20	15/03/10	09:00 10:00 AM	01:29:42

To guarantee “reliability and validity”<sup>35</sup> in conducting the interviews, consistent procedures were adopted to ensure that all of the participants were exposed to the same process. Therefore, the following procedures were developed; a convenient time and location were considered for both the interviewees and the interviewer when scheduling interviews. Eighteen interviews were conducted on The Saudi Autistic Society site whereas the other two interviews were conducted at one of the private autism centres that was the most convenient for the interviewees. A text message was sent to the participants a day before their interview as a reminder.

Formal welcoming, that befits the Saudi tradition by providing the participant with Arabic coffee, dates and chocolate along with informal chatting on general topics, such as the weather or traffic, took place before the interview. The aim of this is to comfort the participant and to give her the sense of closeness and welcoming. The mothers were interviewed face-to-face for each appointment. A brief introduction about the interviewer was the starting point, before the information was given to the participants about the aims of the research. Reassurance was also given that all of the information generated from the interviews would be treated in confidence and used for research purposes only. The participants were also told that neither the interviewee's name nor the child's name would be referred to directly within the research. The mothers signed a consent letter in order to get their agreement to be interviewed face-to-face, for audio-taping the interviews and subsequently to participate within the training programme, (see Appendix D for more information about the consent letter). The mothers also completed PSI/SFs and filled in the study questionnaires before the interview started.

The interviewer made a conscious attempt to perform the research so as to create the same physical atmosphere for all of the interviewees. However, this proved not to be possible in practice. This was because of maintenance work taking place

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<sup>35</sup> In place of reliability “another statistical concept” I imply a systematic and regular interview routine for each mother's interview process.

at the Saudi autistic society, which in turn affected the peace of the interview room and sometimes the privacy of the interviews because a member of staff was sharing the same room; this happened three times. The other two interviews that had been conducted at one of the autism centres also faced some difficulty because the interview was conducted at the centre's Head Office. Despite this, the staff were cooperative and supportive. During the interview process, the staff left the office. Providing the Arabic welcome and coffee was not possible at the autism centre, but a comfortable physical environment eased the flow of the interview and affected both the interviewer's and the interviewee's interaction and concentration. However, the interviewer tried to be even more sympathetic and interested in the interviewees' experiences and stories in order to minimise outside factors disrupting the flow of the interview. An apology was given for any inconvenience or interference that might disturb the interviewee.

Not only does the physical environment affect the interview flow and outcome, but also the interviewer's and the interviewee's personality and characteristics have a major role. Bryant and Charmaz (2010) emphasises the importance of this interaction in both the process of interviewing and the outcome of the interview. The following is a reflection on my personal experience of interviewing the mothers who have a child newly diagnosed with autism. In all of the interviews, the first few minutes at the beginning of the process is where both partners examine each other and draw on the types of interaction that might coexist between them. It is an unconscious process that might be called the 'first impressions'. The interviewer considers herself to be a polite speaker and a good listener, who has a confident and brave personality. This self-definition might, to a certain extent, be similar or different from what the participants perceive. However, whatever impression the interviewer has left affected the interview in some way or other.

Some personal observations were made in order to maintain objectivity, such as distancing oneself as being specialised in the Autism field. The mothers tried to elicit information concerning advice or to clarify any misconceptions of the nature of autism which could not be given, as such information may prejudice the

situation. Previous work experience was found to be a disadvantage as it may lead the interviewer to influence the interviewee with knowledge in the area that the study is testing. Furthermore, allowing the mothers to leave without providing them with some basic information is egocentric and does not reflect a proper level of professionalism.

The emotional journey of accompanying the participants was taxing. One of the reasons for this is because of the large degree of difficulty to remain emotionally objective and uninvolved. There was a constant urge to facilitate more than what was required. One such example is that after the fourth interview with the mothers, trust had been earned, whereby the interviewees felt free to discuss some of their personal issues which were not directly related to the study objectives. This discussion was continued for one case via a telephone call, on the mother's request.

Another observation was that the mothers' personalities and characteristics also had a significant impact on the interviewing process and outcomes. Some mothers were talkative, while others did not have a strong independent personality which became apparent from the actions and decisions they had undertaken in order to face their children's problems. Others were less-talkative, hesitant and repetitive in their accounts. This led to rephrasing some of the questions in order to elicit the answer and to try to motivate them to talk and provide examples. Therefore, the interviews varied in length, with some lasting more than one hour and some about thirty minutes, with the average being one hour as had been pre-arranged with the interviewees.

From these observations, the mothers' different reactions towards the interview and interactions with the interviewer led to some critical questions that needed to be answered: What is the motivation behind the mother's acceptance to come and be interviewed? Is there any particular agenda that they hoped to accomplish? What do they anticipate and expect from the interviewees? Mostly, being interviewed could be part of their journey to look for a cure for their children, although other reasons might coexist. For instance, one mother mentioned that

she came to the interview to offer help and support to both the researcher and to other mothers who are in the same situation. Another mother felt that her case was worth considering and that the researcher would benefit from her experiences. Some were looking for advice as to what they should do after getting the diagnosis. Quite a few wanted to be trained, and the interview process was part of the overall recruiting process in which the mothers were told that the researcher is interested in interviewing mothers who are willing to become part of an upcoming training programme. Several other agendas might co-exist as it is impossible to predict what people have on their mind.

It is worth mentioning that in addition to the previous explanation of the interview process interviewees were encouraged to speak freely and without limitation. All interviews were structured to be conducted following the same direction, starting with the mothers' experiences of getting the diagnosis, followed by their definition of autism and its resultant problems, then moving on to the parenting system and ending with current and future services. The interviews with the mothers were enjoyable and not a difficult task. The mothers were co-operative, flexible and had a genuine interest in finding out about the outcomes of the research.

The researcher was also concerned about leaving the mother with an acceptable experience. Each participant was given a chance to contribute, add or ask what they think the researcher might be missing throughout the interview. At the end of each interview information about existing services or educational materials was circulated. For instance, the mothers were informed that there is a support group held on a monthly basis which is free to attend and the contact details was given to the mothers. Also, reiterating the confidentiality aspect and emphasising that without their help the researcher would not be able to continue with the study. The twenty interviews were each audio-taped and lasted between eighty minutes maximum and thirty minutes minimum. The experience of interviewing the mothers, who have different reactions towards their problems, enriched the researcher's view, expanded her interview skills and brought valuable data to this study.

The next step after interviewing the mothers was to find a person willing to transcribe the interviews in order to help the researcher analyse them. This task was time consuming and expensive because of the difficulty due to the unavailability of people committed to completing the transcription in due time, and also because of the cost of the transcription. Of the twenty interviews that were transcribed, only five transcriptions were translated from Arabic to English. Transcribing and translating interviews were among the most difficult tasks of the field work process in that it often impeded the progress data analysis step of the research. Therefore, the delay made it difficult to code, analyse and interpret the responses and to compare them with the information and data. Despite the fact that transcribing and translating interviews were difficult, many strategies also had to be adapted in order to read the interviews and to understand the data. One such strategy that was employed was to do a content analysis using an exact word-for-word translation to record the data. By doing this, five Arabic interviews were undertaken taken without actually being transcribed. The content of these interviews was the same and the actual loss of power from the procedure from just listening to the taped interview was quite low.

As discussed earlier, constructive grounded theory was the best instrument to analyse both the interviews transcripts and the questionnaires in order to be able to design a parental training programme, which is the main focus of the study. The next section highlights the procedure for devising the training course.

#### **4.4.3 Devising the parental training program**

As discussed previously, one of the study's main aims is to identify the mothers' needs in relation to their children's difficulties and to enhance their ability to help their children via training that will lead to an easy to implement home-based early intervention. However, designing, developing and delivering a training programme is a challenge that requires considering various important issues. This is because the mothers' needs are not the only essential elements towards the design of the training course. Other concerns that might be encountered when developing such a programme include the mothers' diversity in their educational

level, age, personality type and socio-economical level. In addition, the specific emotional needs that emerge from their child's difficulties might require greater consideration. Another concern is that the researcher plays multiple roles in the current study, as she is not only the researcher but also the programme designer and facilitator at the same time. In addition, the cultural context, the Islamic perspective and adult educational theories are also contexts that need to be examined when devising and implementing the training. This is because the aim of the training does not only focus on teaching specific knowledge and skills to regular students in an educational setting who are aiming for an academic certificate or employees in a career developmental training course that is proposed to enhance their working skills. The situation here is far more complex; the trainees are the mothers of children newly diagnosed with autism and that makes them special cases that have special requirements that need to be met at this critical stage, for both themselves and their children. The following paragraph discusses these concerns in detail, as each of the previously illustrated subjects has its own impact on the development of the programme and its efficiency later on; a full description of the training is covered in Chapter 6.

The process of devising the training encompasses some straight forward procedural steps, such as the programme venue, timing and catering, whilst other steps were more technically complex and interrelated. Assuming that identifying the programme components should be the first step in devising the training course would lead to examining and understanding the participants, their needs and their characteristics, and then link them together in order to generate the programme objectives. Indeed, the generating programme objectives would lead to the further step of designing the programme sessions. However, the programme objectives, the participants' characteristics, and the researcher's role would again come to the surface with the aim of identifying the instructional process of the programme delivery. Having completed these steps, devising and implementing both the ongoing evaluation and the final evaluation would be the last step within this unified process. This unified process exemplifies the constant comparison steps throughout the analysis process, which is one of the main features of the constructivist GT approach.

Technically, in order for the researcher to establish a clear understanding of the program’s participants different strategies were adopted. First, examining the data obtained from interviews, questionnaires and the PSI/SF led to identifying the mothers’ demographic characteristics and needs. This examination helped the researcher in drawing a clear image and a sound understanding about the mothers who would attend the training course. For example, in relation to the demographic characteristics the participants varied in terms of their socio-economical level, education level and personality type, where they almost all homogeneously reflected the age group between 20 and 30. Table no (11) illustrates the respondents’ demographics. This diversity within the participants’ backgrounds was considered when developing the training.

Table 9 Respondents' Demographics

Socio-economical level was determined by participants’ husband occupations.

	<b>The mothers’ educational level</b>	<b>Socio- economical level</b>	<b>Age</b>
<b>1</b>	Graduated	Engineer	32
<b>2</b>	Graduated	Retired	45
<b>3</b>	Graduated	Officer	27
<b>4</b>	Graduated	Employee	35
<b>5</b>	Graduated	Employee	33
<b>6</b>	Graduated	Officer	25
<b>7</b>	Graduated	Employee	36
<b>8</b>	Graduated	Pharmacist	30
<b>9</b>	High school	Officer	28
<b>10</b>	High school	Governmental support	32
<b>11</b>	Middle school	Physician	28
<b>12</b>	Middle school	Worker	36

An examination of the data revealed and identified the common needs of the participants. These needs were grouped under three major categories; emotions, information and skills. These three main elements construct the programme components. Each element was expanded in order to help address a broader range of the mothers’ needs in relation to that specific area. Each participant had her own personal characteristics and needs; however, meeting all of the participants’

needs via this training course proved not to be possible. This is because the aim here is to focus on developing a training course that targets the mothers' common needs and is not an individually tailored training programme.

Having said that, the researcher's role is also one of the concerns in the process of devising the training course. The personal assumption taken is that the mothers would attend such a course, not only for the purpose of gaining knowledge, but also to look for hope and solutions to help their children. This assumption was built up from the interviews, in which each interview raised questions that included; what is the best way to help my child?, do you think my child would be better with intervention?, do you think what I am doing is good for my child?. In addition, there were hidden messages, where the mothers' indirectly inquired whether this programme would be a solution or a useless waste of time. All of these were added pressures that were encountered whilst developing and delivering the training course. Nelken (2009) argues that the adult student is not 'a blank sheet'; their learning is affected by what they bring with them to the learning environment. Indeed, it is the teachers' responsibility to understand the people that they deal with before deciding what they need to teach them. Thus, this also correlated with the use of the constructivist grounded theory approach, where one of its emphases is that the role of the relationship and the interaction between the researcher and the participants cannot be ignored. The difficulty was in being empathetic with the participants whilst remaining an objective developer and programme facilitator.

Indeed, the methodology for the data collection was chosen to obtain a more objective role in order to gain insight into the mothers' common needs and characteristics at this stage. The triangulation method, which uses three methods, was chosen in order to reduce the possibility of data bias and to aid in the objectivity by shifting to the position of being both developer and facilitator. However, Rogers' (1969) philosophy of the learning facilitator was that confronting strengthens the objective position. The philosophy is of a holistic flexible view regarding the facilitator's role and qualities. According to Rogers (1969), the facilitator is:

- A learning resources organizer where s/he prepares and makes a range of learning resources available to fulfil participants' purposes.
- A learning climate creator where s/he is able
  1. To clarify both individual and group learning purposes.
  2. To trust the participants, value and accept their diversities.
  3. To use the participants' motivations as a moving force for their learning.
  4. To be a participant learner and member of the group by sharing thoughts, feelings and knowledge with them.
  5. To be able to understand the participants' feeling of conflict, fear, pain, anger, etc and to be empathetic.
- Counsellor and advisor with experience in the field.

The previous illustration is related to the researcher's position within this study, particularly in relation to the relationship with the participants. Therefore, developing a trust and a good relationship with participants is essential in order to be able to support and help them. Indeed, taking more of a role as a facilitator with a set of expertise, rather than as a teacher or trainer was more of the approached used in this study.

Knowing the participants and identifying their needs is essential in order to determine the course components. It is also equally important to use the obtained knowledge in determining the design and the delivery approach of the training course. Therefore, consulting andragogical principals is essential at this stage. Most studies conducted within this field focus on academic or educational purposes and career development courses, in which the objectives and outcomes are different from what is intended to be provided and achieved within the current parental training course. However, a closer examination of these studies has helped in adapting some of the implications to the current training course. Indeed, learning theories and teaching theories, according to the literature, are different, where the first focuses on how the learner learns the 'learning style' the second emphasises the nature of teaching and the teacher's role. However, there is a correlation between these studies in which teacher teaching theory is usually affected by the tutor's adopted learning theory (Knowles et al., 2005). Thus, having justified the position of the learning facilitator, the following is an

illustration of some adapted ideas from both learning and teaching theories that have been considered when devising the training course, clarifying that there is no 'one size' framework that fits all educational situations and that each case has its own objectives and participants' purposes that differ from other situations.

A general understanding of the adult learning style and how this knowledge would be applied to a learning situation were examined. For example, Kolb (1984) has developed a model of experiential learning based on the idea that experience is central to adult learning. The learning occurs when experience transforms to knowledge and this transformation is cyclic and occurs in four learning stages;

1. Concrete experience 'the involvement in active experiences'.
2. Observation and reflection when an individual reflects on experience.
3. Abstract conceptualisation via integrating observation to create a concept based on observed experience.
4. Testing implications via applying concept in decision making and problem solving.

Based on that, Kolb (1984) suggests four learning styles that correspond to these four learning cycle modes. These are assimilators, convergers, accommodators and divergers. However, Loo (2004) suggests that an effective learner incorporates the four learning styles within the learning situation instead of relying upon one favoured learning mode. Another adopted perspective is Knowles et al.'s (2005) theory. Knowles is one of the recognised theorists within the field of andragogy and constructs his theory on adult learner characteristics. His model suggests six core adult learning principles. These include:

1. Learner need to know (why, what, who) to learn something.
2. Learner self-concept (autonomous and self-directing).
3. Learner prior experiences role.
4. Learner readiness to learn.
5. Orientation to learning (life-centred and problem-centred).
6. Motivation to learn.

All of these core adult learning principles should be considered within the context of individual and situational differences along with learning goals and purposes. Thus, based on learning theories and principles, adult's core needs are central to andragogy principles. This is because adults will be motivated and ready to learn when the learning meets their needs (Knowles et al., 2005).

The previous illustration reflects one of the most important aims of the current study in developing a parental training course that meets the mothers' needs in relation to their child's difficulties. This is because having a child who has been newly diagnosed with autism is a problematic issue to the mother. The mothers' efforts in confronting this problem and in trying to find a solution, indeed reflects a fundamental learning style that adults generally favour, which is the problem-solving orientation learning style (Knowles et al., 2005). Based on that, the process of identifying these needs via different research methods has helped in formulating a training course by considering the mothers' needs within the context of adult learner theory principles in order to understand the participants' characteristics and needs and has used them to create the learning objectives and a learning environment.

Therefore, the following illustration exemplifies the researcher's understanding and concerns in devising the training course and the steps that have been undertaken based on the acquired understanding. The training programme was planned to run as follows: the training was designed to cover five main sessions, divided into six weeks, to be conducted for two hours a day, for two days a week. The following gives a brief illustration of the training implementation procedures. However, a detailed illumination will be discussed in Chapter six.

**I Pre-Implementation process aimed to:**

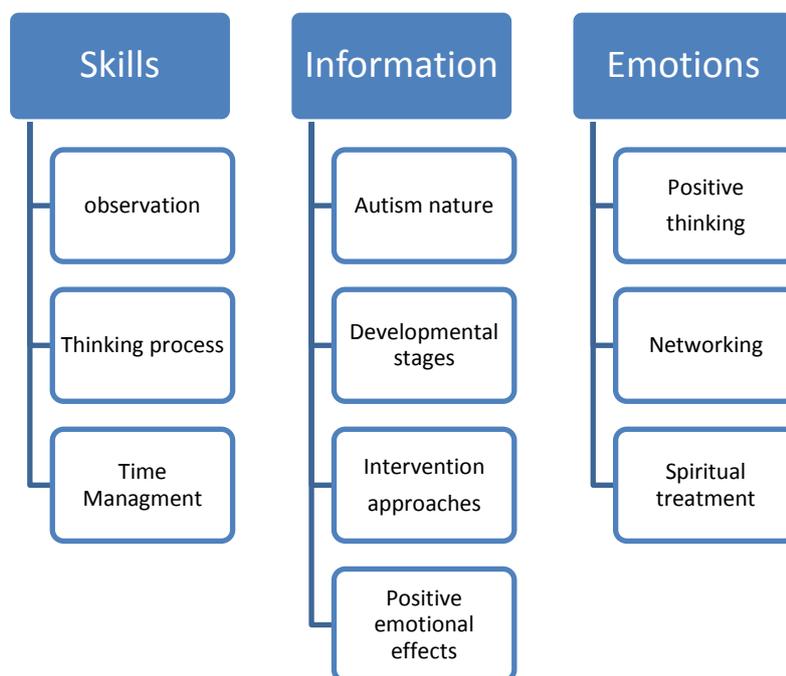
1. Identify the mothers' needs in general
2. Identify the participating mothers' characteristics and demographics.
3. Identify the training program components and design of the sessions.
4. Determining the training length, time, days and dates.
5. Organising the physical setting and the food and drinks catering.

## II Implementation Process:

1. Prioritizing the training components in a coherent order as follows:
  - a. The trainees and trainer getting to know each other.
  - b. Illuminating the aims of the training and its process of development to trainees.
  - c. Introduce the thinking process as an introductory measure to address the importance of understanding feeling and its effects on one's behaviour.
  - d. Discussing coping strategies in the light of the Qur'an and Sunnah as this reflect the Islamic and cultural context of the mothers.
  - e. Highlighting the family role:
  - f. Providing general information about the nature of autism, available interventions and the child developmental stages in relation to autism.
2. Providing the mothers with handouts and relevant printed materials.
3. Designing exercises to implement observation, prioritizing and developing home-based intervention plan skills.
4. The mothers' input and concerns were welcomed and addressed.

In fact, the researcher had to develop a strong foundation before exposing the mothers to the information and skills that were required to meet their children needs. Therefore, the first session within the program was covered in four meetings. The rest of the sessions were concerned with the core information about autism, its nature, its characteristics and educational approaches along with observational, flexibility, and the prioritizing intervention objectives skills that led to developing the home-based intervention program. The following diagram summarises the training course components.

Figure 10 Main Course Components



Indeed, following adult learning theory advice, the current training course has been through several planning phases. These were: starting with the identification of the parental common needs and characteristics phase; moving towards the designing phase and then the implementing phase; and finishing with the evaluation phase. The evaluation phase is examined within the following section.

#### 4.4.4 Evaluation strategies

As discussed earlier, several tools were used to identify the parental needs in relation to their children's' difficulties. These needs have been accumulated to devise and implement a parental training programme. The next step was evaluating the programme's usefulness to the participants and to ensure that it is beneficial to the parents by providing them with what they need and expect to receive. This measure is also important in the finding programme's strengths and weaknesses, as well as in improving both the programme components and its delivery. The study's results can then contribute in applying the generated knowledge into practice within the Saudi context. Indeed, two methods were used

to evaluate the training programme; the evaluation forms that had been developed by the researcher, and the PSI/SF (parent stress index short form). The PSI/SF was used along with the evaluation forms, and this psychometric tool will be discussed later in further detail. The following paragraphs define the evaluation process, its importance, as well as giving a detailed description of developing, implementing and analysing the tools.

Programme evaluation is a strategy used to estimate the relative efficiency of any delivered work. It has been widely used by professionals to evaluate programmes within the context of human services (Monette, 2008). Thus, developing a parental training programme that will lead to an early intervention home-based programme, which is the main concern of this study, is considered to be a human service. Royse (2006) argues that it is vital for professionals to examine a programmes' effectiveness and its impact on the client, as this is how improvements come to both the clients and society. Program evaluation is the systematic collection of information about the activities, characteristics and outcomes of programs in order to make judgments about the program, improve the program effectiveness, and/or inform decisions about future programming (Patton and Patton 2002).

Evaluations vary in their purpose and might include curriculum components assessment, implementation effectiveness of instructional and teaching methods, trainer experience and performance, training influences on trainees and programme costs and benefits. In addition to that the evaluation findings would serve as the basis for decision making and improvement (Shadish, 1991). Scriven (1991) believed that evaluation has two functional types; formative and summative. Formative evaluation aims to provide evaluative information that could be used in improving the program. This kind of evaluation takes place during the development stage of the programme in which feedback is obtained and used in finding ways for programme improvement. Summative evaluation, on the other hand, is conducted after implementing the programme in order to determine whether it should continue to run or be discontinued. Worthen et al. (1997) stated that "both formative and summative evaluations are essential

because decisions are needed during the developmental stages of a program to improve and strengthen it, and again, when it has stabilized, to judge its final worth or determine its future" (pp.14 & 15).

Thus, considering that the main focus of the evaluation process within this study is to assess and critique the programme components and its delivery for meeting the participant's needs, the previously mentioned formative and summative evaluation techniques were both used. Therefore, two evaluation forms were developed by the researcher; the session evaluation form and the entire training evaluation form. The main criteria that had been used to determine the evaluation form components were programme objectives, components and instructional process. Moreover, both structured and unstructured types of questions were used in these forms. Structured designs vary in their format and are relatively easy to respond to, which adds to the accumulating and summarizing of the responses for what seems to be a straightforward process. However, respondents might be limited in their responses to specific answers which may not accurately reflect their opinion. This difficulty also affects the researcher's ability to understand and analyse what the respondent really means.

In contrast, unstructured design is limited in its format, and is more difficult to create and analyse. Responses are usually affected by the respondents' understanding of the question; also, answering such types of questions requires the time and effort of the respondents. However, the unstructured format provides the respondents with a space to express their ideas and thoughts (Trochim, 2006).<sup>36</sup> These two types of questions give the mothers the opportunity to freely express their perspective about the training. Indeed, using both types of questions would provide the researcher with more in-depth information that shows the impact of the program activities and to make sure that sessions are working as intended. The following paragraphs will highlight the evaluation form individually.

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<sup>36</sup> <http://www.socialresearchmethods.net/kb/index.php>

The sessions' evaluation form was given out after each session with the aim of finding areas of improvement. This form consists of two parts; part one includes fourteen statements to be ranked according to a five point Likert-type rating scale (strongly agree to strongly disagree). These statements cover the sessions, the goals, information, exercises, the organisation, the venue and the presenter's capability. In part two, the mothers were asked to answer six open questions about what they had learnt, their likes and dislikes, difficulties they had encountered, things to be considered within the next session and finally to provide suggestions for improvement in general. (See Appendix E for more information about the sessions evaluation form.)

The feedback was examined after each session with the purpose of identifying improvements that could be applied to the following programme sessions. Indeed, this part of the evaluation could be seen as an ongoing formative evaluation which provides the researcher with suggestions and information for development, not only during the training implementation stage, but also after the programme has been finished. Moreover, it is also consistent with the GT approach principles of using consistent comparison and ongoing data analysis.

The second form was for the entire training evaluation, and that was given at the end of the training with the aim of generating a final thought about the programme's effectiveness and the mothers' satisfaction. This form was designed to be more comprehensive and to cover the programme objectives, information, skills, exercises, training strategies, organisations, training time and length, and the effects on the trainees understanding and beliefs. The form was in three parts, and each part contained a heading, in which the mothers are thanked for participating in the program and highlighting the importance of completing the questionnaire, emphasising the importance of their opinion in improving the established service. Part one consists of seven structured questions that cover contents, objectives, information and skills. Part two is constructed in four main statements, with each statement being followed by sub-statements to be ranked in relation to the main statement according to a five Likert-type rating scale

(strongly agree to strongly disagree). These statements cover the sessions, the goals, acquired information, exercises, the organisation, implementation, acquired skills and the presenter's capability. Part three consists of two types of questions; filter questions about the length and time of the training period, and open ended questions to provide general feedback. For more information about the overall evaluation form see Appendix (F). In fact, the researcher accumulated both formative and summative evaluation types, along with a variety of questions designed to obtain a clearer and broader image about the mothers' perspective and satisfaction toward the training programme.

Indeed, the importance of the evaluation step emerges for several reasons within the context of the current research. First, evaluating programme effectiveness is an essential part of the programme development process. The evaluation process generates the results that potentially answer one of the research questions, which emphasises how programme effectiveness could be evaluated. Second, a parental training programme being developed is relatively new within the Saudi context and as such is going through a pilot stage in which the planning and the implementation process need to be documented and evaluated. Third, by evaluating established services, the current programme will be able to suggest and provide them with alternatives and improvements. Fourth, the mothers know whether the training meets their needs and, as the programme clients, their evaluations are essential. Thus, the previous illustration of the significance of the evaluation emphasises that the aim of research in education is not only in generating knowledge, but also in finding better ways and transferring them to practical knowledge (Royse, 2006).

Despite the fact that evaluation would establish opportunities for improvement in both the programmes' providence and policies, it does not automatically ensure that participants will learn and benefit from the training programme, thereby highlighting one of evaluation's limitations. Other limitations might include question bias, question misunderstanding, the truthfulness and clarity of the responses and intentional deception. These limitations can all contribute to inaccuracies in the data obtained from the evaluation. Therefore, using another

measure would compensate for some of these limitations. The following section explains the psychometric tool that has been used along with the evaluation form in order to determine the programme's effectiveness.

#### **4.4.5 Parent Stress index short form:**

The Parenting Stress Index/Short Form is an abbreviation of the Parenting Stress Index full-length test. The short form of the PSI was developed to meet the needs of clinicians, researchers and professionals in different settings as a brief assessment tool that could be applied quickly and easily. The aim of the PSI/SF is to measure and evaluate the parent-child system by focusing on the parent, the child and their interactions. These three factors are the subscale components of the PSI/SF and were labelled parental distress, parent-child dysfunctional interaction and difficult child. The PSI/SF is guided by a theoretical model of the determinants of dysfunctional parenting. This model emphasises the importance of the parent-child system and the factors that shape this parenting system in both child development and the parenting role. Abidin (1995) argues that the child's temperament, parental personality characteristics, and family structure and functioning affect the development of a dysfunctional pattern of the parenting system. Therefore, devising a technique that could identify the parent-child system is relatively important for both early identification and early intervention (Abidin, 1995).

Linking the previous illustration to the current study aim of devising a parental training programme that will lead to an early intervention home-based programme based on the parental needs and perspectives using such psychometric tools, is relatively related. This is because both the current study aim and the theoretical model of the PSI/SF have a similarity in terms of their focus on parenting experiences. Therefore, using the PSI/SF will serve two purposes: first, close examination of the parent-child interactions, and second, the PSI/SF which was applied pre and post the training programme to evaluate the programme effectiveness. Despite this, the PSI/SF has not fully established empirical validity. Literature within the special educational needs area generally, and the autism domain specifically, suggests that the PSI is valid for the current

study population. Moreover, the multicultural use of the PSI for different cultural samples shows comparable statistical characteristics to those described in the parenting stress index, third edition professional manual (Abidin, 1995). This would also suggest its suitability to be applied to the Arabic version of the questionnaire within the Saudi context.

The research participants were exposed to the PSI/SF form pre and post the parent training programme. The form consisted of 36 questions. However, the Arabic translation version of the PSI/SF was sometimes not clear, and the mothers found it difficult to understand the meaning of some of the questions and how they should respond to them (see Appendix G for more information). Indeed, this reflects another limitation of using PSI/SF along with its limited empirical validity. Therefore, the PSI/SF a psychometric tool was used along with the devised evaluation forms to measure training programme effectiveness and to compensate both evaluation forms limitation and the PSI/SF.

Responses obtained from the PSI/SF were scored, profiled and interpreted according to the Stress Manual. Responses obtained from the evaluation form were coded, analyzed and interpreted following the constructivist grounded theory approach, in which theoretical links between categories and all data collected throughout the study were conducted in order to deeply understand the mothers' needs in relation to their children's difficulties and the process of developing and implementing a parental training programme that aimed to meet these needs, which led to a home-based early intervention programme. Further details of both the PSI/SF scoring, profiling and its interpretations, and the evaluation forms' coding, categorising and interpretation, are discussed within the analysis chapter.

## **4.5 Ethical Considerations**

This research pursues the following ethical steps: the study went through the process of obtaining the ethical approval of the Brunel University Research Ethics Committee, and the Research Ethics Committee of the King Faisal Specialist Hospital in Jeddah, in order to be able to access the research interview

sample. Another step that had to be undertaken was obtaining the participants' consent. All twenty of the participants that took part in the interviews signed a consent form. This consent form described the procedures in the study, promised confidentiality, and informed the participants that they could withdraw from the study at any time. The purpose of the study was clearly stated within the contents of the consent form which was carefully reviewed with each participant before conducting the interviews, (see Appendix D for more information). Both the participants' and their children's names were not used; instead a label was used by the researcher to maintain the participants' privacy and confidentiality. In addition, it was made clear, not only through the consent form but also through verbal communication with the participants, that the researcher is available to address any concerns and questions that the participants' might have.

The privacy and confidentiality procedures were also applied to the other data collection methods; i.e. the questionnaires, the PSI-SFs and the evaluation forms, as they all include information about the participants. Those who completed questionnaires were not required to disclose either their names or their children's names. The PSI-SF and evaluation forms were treated with confidentiality as there was no outside access to any of the research materials. Indeed, the researcher was conscious in considering the participants' rights, both ethically and culturally.

## **4.6 Summary**

This chapter has summarised and provided the reader with a clear map of the research journey that was undertaken. The major steps that have been discussed within this section to exemplify the current research conduction are:

- An overview of grounded theory approaches, its implications and limitations.
- The rationale for the use of constructivist grounded theory to address the primary research question.
- The procedures used in the study for participant recruitment, interviews, questionnaires and data analysis.

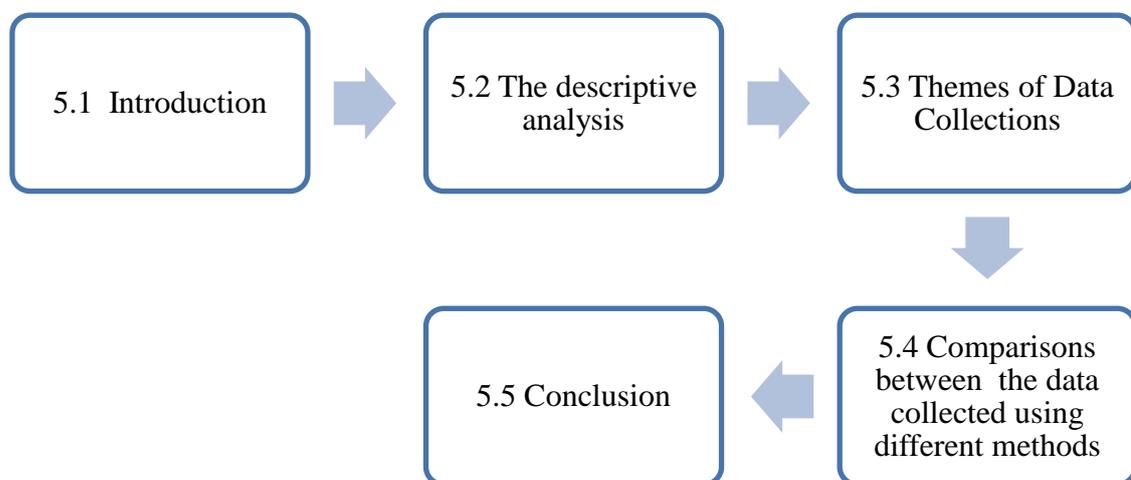
- The issues considered and the procedures used in designing, implementing and evaluating the training programme.
- The role of the researcher and the ethical considerations for this study.
- Finally, a previous systematic approach aimed at meeting the standards of research goodness was undertaken.

# Chapter 5: Analysis

## 5.1 Introduction

Chapter four highlighted the research protocol that had been proposed to gather the current study data. The focus of attention within this chapter is directed towards a detailed description of the coding and analysing stages within the context of constructing the grounded theory protocol. Coding and analysing covers a variety of multi-methods that have been used to conduct this work, such as questionnaires and interviews. Three major themes were generated from the collected data. These include difficulties, needs and actions. The following figure illustrates the basic outline of the structure, based on the various methods and themes.

Figure 11 Structure of Analysis



## 5.2 The Descriptive Analysis

In the light of this research, the main concern in developing a parental training programme is the process of giving meaning to the data collected from the questionnaires starting with the coding then moving to the analysis and

interpretation. Therefore, before moving to the coding and analysis steps a brief review of the purpose of using questionnaires as one of the study data collection methods is warranted at this point. Detailed descriptions of the procedures of development, sample recruiting<sup>37</sup> and conducting the interviews, have been discussed previously in the methodology chapter (see prior discussion in Chapter 4).

Accordingly, the aim of using questionnaires is to identify the parents' ongoing needs in relation to their children's difficulties. To the best of my knowledge, identifying parents' needs in relation to their children's difficulties within the context of the Saudi culture has not yet been examined, as previously stated in Chapter four. Indeed, the questionnaires were designed to be anonymous for ethical consideration, and were sent to the general population regardless of the child's age, gender, and autism severity level. However, the responses obtained from the questionnaires' are not necessarily a representative sample of the population of families of children with autism in Saudi Arabia. Despite the modest number of questionnaires' collected and used in the research, the results obtained from the sample could be seen as indicative in terms of its number rather than reflective of the entire population of families of children with autism across the kingdom's regions. Furthermore, it is important to acknowledge that receiving duplicate copies means a possibility that an error that might occur. Examples that resulted in duplicated questionnaires occurred in situations in which the questionnaires were re-sent for some centres due to the limited number of responses received. Moreover, some children might receive services from more than one centre, and so the possibility of filling in another copy of the questionnaire could be expected. In addition to the mailed questionnaires, the questionnaires were also launched online, which presents yet another possibility that might have led to more than one copy being completed.

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<sup>37</sup> Although the total number of received questionnaires is 251, unanswered questions in some of the questionnaires were possible. Therefore, the number of responses might vary for each question accordingly.

Three main areas have been addressed within the questionnaires: family demographical information, difficulties facing the child and the parents and finally the parents' experiences and satisfaction of the currently provided services. Most of the included items varied in nature between quantitative and qualitative. However, even the quantitative part of the survey would show some numerical indications. These indications would be interpreted qualitatively, as the focus here is in identifying and understanding the parents' needs more than calculating them.

Several techniques were used in coding and then analysing the questionnaire responses. First, all of the received responses were uploaded manually online to Smart-Survey<sup>38</sup>, with the aim of obtaining a graphical result of the questionnaires' responses. This was followed by an initial coding and analysing in order to examine the parents' responses and to identify their needs and their actions towards these needs. The information collected was compared with information that had been obtained from the interviews with the mothers in the later stages, as this would help in exploring any possibilities that would lead to the developing of a valid interpretation and conceptualisation.

### **5.2.1 Part One: Demographical Information**

The questionnaires were divided into three parts; see Appendix (B) for more information. The opening part consists of thirteen questions in total. The first nine questions focused on the demographical information that included the age, gender, number of children in the family, the child's sequence in the family, the parents' level of education and the parents' occupation. The other four questions are interrelated and focused on the diagnostic process and the child's age at diagnoses. The following sections give an insight into the demographics of the respondents.

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<sup>38</sup> Smart-Survey is online survey software where users can create, publish surveys and then view their results graphically. <http://www.smart-survey.co.uk/>

### 5.2.1.1 Who fills in the questionnaires?

*Who is filling-in the questionnaire?* The responses indicated that 79.1% mothers, 14.2% fathers and 6.7% others completed the questionnaire. This data can be interpreted in two different ways. The first implication is that the mothers are mostly the primary caregivers when compared to the fathers or other people who might be in charge. Another interpretation, taking into consideration cultural insight and knowledge, is that twenty-seven of the thirty-four centres that were contacted to send out the questionnaires to the families were run by female professionals, and were in institutions providing services run solely by females usually targeting the female client, which in turn might suggest that mothers would be the first point of contact. Therefore, this might explain why the majority of questionnaires were filled-in by the mothers. Consequently, the decision to provide training programmes for the mothers only was more appropriate within the current study as this perfectly fits with the Saudi culture. The following table shows the statistics retrieved from the Smart-Survey software in relation to this query.

Table 10 Percentage of Respondents Based on Role in Child's Life

	Response percentage	Total responses
<b>Mothers</b>	79.1%	200
<b>Fathers</b>	14.2%	35
<b>Others</b>	6.7%	16

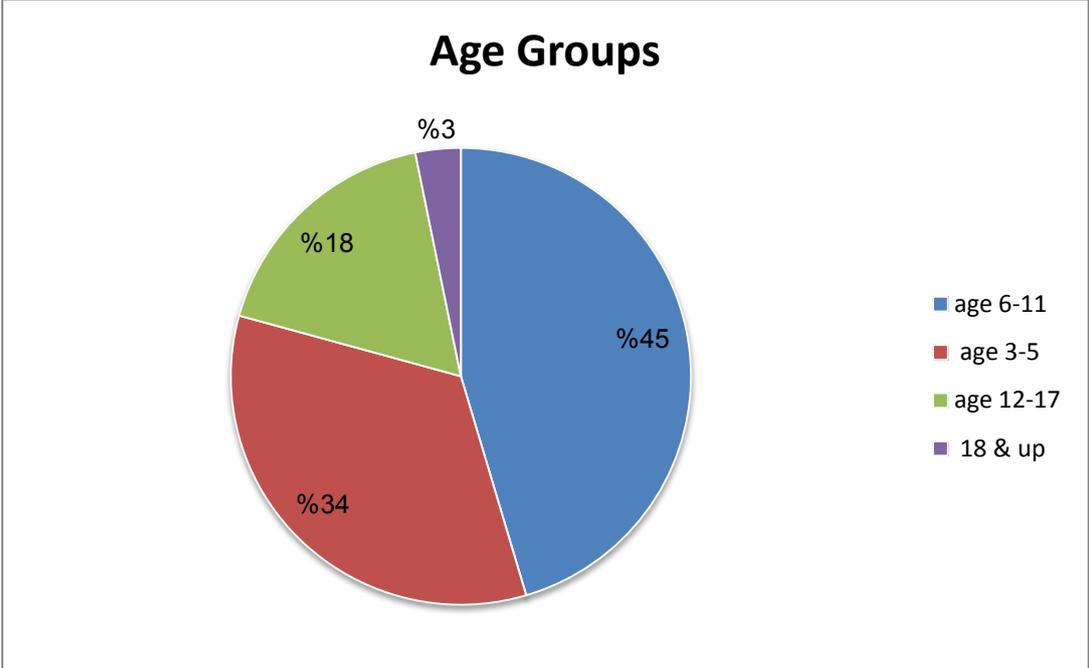
Statistics based on **251** respondents

### 5.2.1.2 Child's age

Figure (12) shows a histogram of question one concerning the *child's current age*. According to the responses, the four age groups were classified based on the type and level of services that the children should receive according to their age

and according to the education system in Saudi Arabia. These groups are: 3-5 years old is the Kindergarten level; 6-11 years old is the elementary educational level, 12-17 years old is middle and high school level and 18 years old and upwards is college level. An analysis of the data has shown that the age group between 6-11 years old (45% of the respondents) is ranked first, followed by the age group between 3-5 years (34% of the respondents), with the age group 12-17 (18% of the respondents) and the age group 18 or older (3% of respondents) being only marginal to the other groups.

Figure 12 Age Demographics of the Autistic Child



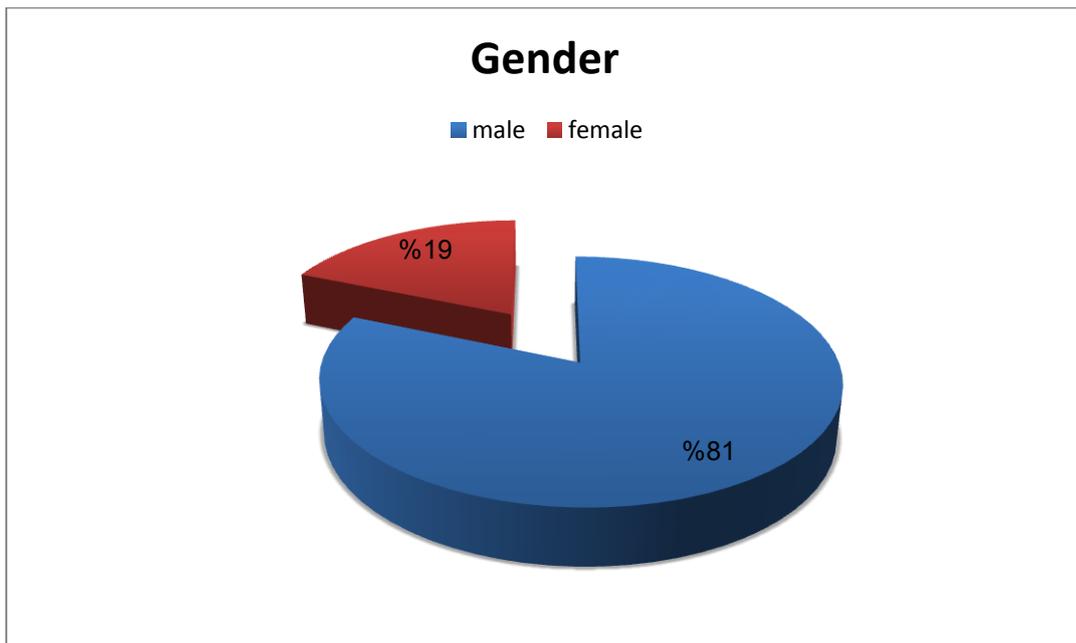
Statistics based on 222 responses

This may give the impression that the major share of the services are provided to the first and second group, while the latter are limited in terms of the services provided to them. Indeed, this might also be interpreted as autism services are relatively new in Saudi Arabia which follows the natural progression in the evolution of the services.

### 5.2.1.3 Child's Gender

Figure (13) shows that the responses on the *child gender question*, where n=245 were represented, and which replicates that a large portion of the questionnaire sample (81.4%, n=199) were male, versus (18.6%, n=46) who were female.

Figure 13 Gender Demographics



Figures based on 245 respondents

These ratios are consistent with what is generally known, that the incidence of autism is more common in males than in females, according to the previously reported rate of a nearly 4-1 ratio of the incidence between males and females (NAS, 2011)<sup>39</sup>. Thus, the aim of this question was to relate this to the cultural perspective on child gender, which will be discussed in relation to other questions later on within this analysis.

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<sup>39</sup><http://www.autism.org.uk/About-autism/Autism-and-Asperger-syndrome-an-introduction/Autism-why-do-more-boys-than-girls-develop-it.aspx>

#### 5.2.1.4 Number of Children in the Family

The family size has been defined by the number of children. Small-sized families are considered to be those who have 1-2 children in the family. Medium-sized families are those with 3-4 children in the family unit and large-sized families are those with more than 5 children in the family unit. As illustrated in the following table, the demographics according to family size showed that almost half of the respondents have medium-sized families (n=96 out of n=214). Of the medium-sized families, 51 families have 3 children (n=51) whilst 45 families have 4 children (n=45). Furthermore, large-sized families who have more than five children and small-sized families who have 1 or 2 children, share the remaining portion of the study sample (n=66 and n= 52) respectively.

Table 11 Demographics of Family Size

Family size	No. Children	No. Families	Total
<b>Small</b>	1	14	52
	2	38	
<b>Medium</b>	3	51	96
	4	45	
<b>Large</b>	5	32	66 214
	6	16	
	7	10	
	8	5	
	9	1	
	10	1	
	11	1	

Figures based on 214 responses

These figures help in predicting the level of care that would be provided to the child with a disability in the family. One could expect that the more children in the family, the greater the care load would be on the parents. Consequently, the quality of care and time provided to the child with a disability would be affected because the child with autism needs extra help and support when compared to a child without a disability. However, one should consider that the family size may vary across the country as stated earlier. The questionnaire sample only covers three big cities in the kingdom. However in small towns and villages, one can

expect that the family size might be different. Therefore, in providing the training programme this factor should be considered.

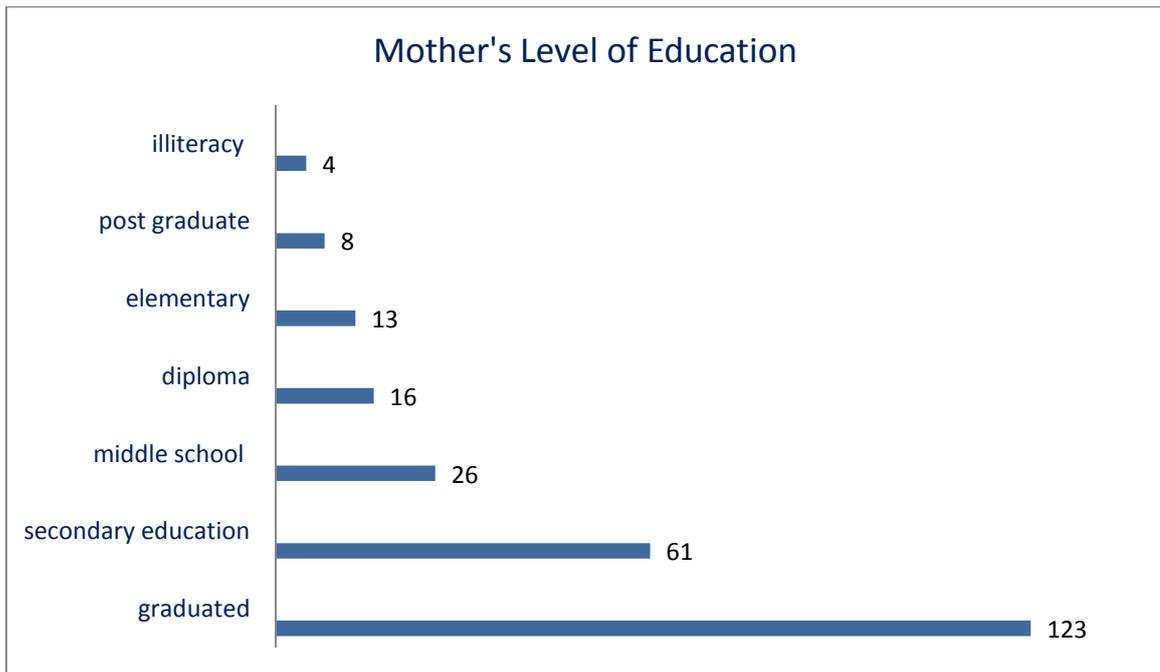
#### 5.2.1.5 Number of Children with Difficulties in a Family

When parents were asked *if there are any other children with a disability in the family*, 21 (n=21) families out of the total sample (n=251) responded that the family suffers from the presence of another disabled child or more in the family. In terms of the difficulty type 7% (n=17) of the responses reported an incidence of autism recurrence in the family. Indeed, one can conclude that the probability rate of autism repetition in the family is quite high within this small sample size.

#### 5.2.1.6 The Mother's Level of Education

The level of education is divided into seven categories. As noted in the following chart for the mother's education level, university education for mothers is ranked first by almost half of the sample, followed by secondary education, middle school, diploma, elementary, post graduate and illiteracy. Regardless of the high proportion of educated mothers represented within this sample, when providing the training programmes the complete range of the mothers' educational levels will need to be represented. For example, in the training programme in which twelve mothers participated, eight of them were graduates, two were high school level and the other two had only a middle school level of education. Indeed, this would reflect the variation in the educational level that such training services should accommodate. A quick comparison between the mothers' level of education and the mothers' involvement at work shows that 20% of the questionnaire sample are working mothers who are mainly teachers or working within the educational sector, whilst the majority are housewives.

Figure 14 The Mothers' Level of Education



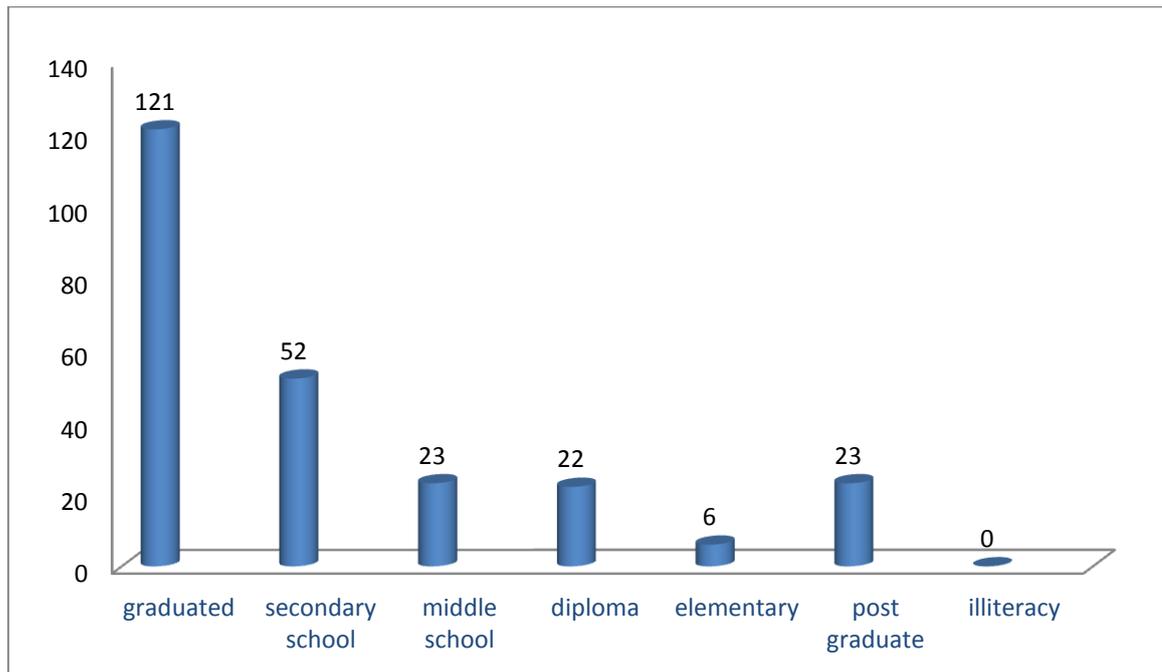
Figures based on 251 responses

A further finding from these figures is the correlation to the family size. It was found that a lower number of children in the family might be associated with the mother's level of education. For example, three of the four illiterate mothers within this sample were classified within the large family group where the number of children in the family is more than 5.

#### 5.2.1.7 The Fathers' Level of Education

The histogram below demonstrates the fathers' level of education. According to the figures, 49% of the sample have graduated and 9% have completed postgraduate level, which shows that more than half of the sample are well educated fathers. Linking these figures to the father's occupation illustrated that 2 of the 247 respondents were not working, whilst the remainder are employees in different areas of work which are very diverse, ranging from senior occupations, for example, doctors and engineers, to simple jobs like workers and drivers.

Figure 15 The Fathers' Level of Education



Figures based on 247 responses

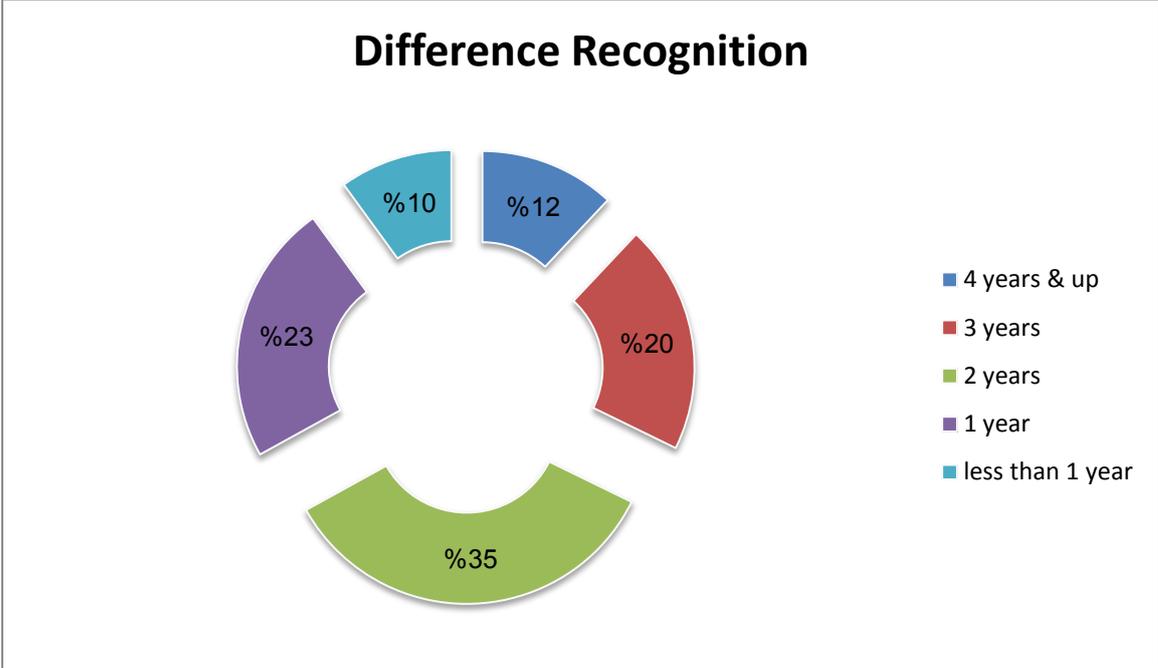
#### 5.2.1.8 The Child's Age When a Difference was First Noticed

Based on the 251 responses, the parents varied in their ability to identify that the child was different. The majority of the parents noted the difference in terms of child development between the ages of 2 and 3 years old. The histogram (Figure 16) shows that 35% of the parents noted that the child was different when s/he was 2 years old compared to 23% of the parents who recognised the difference at the age of one and 20% at the age of three. Those who observed the difference when the child was 4 years old or more was 12% and the parents ability to identify a difference at an early age, less than one year old, was 10% of the sample. Reading through these figures shows that the majority of parents sensed the child's differences at ages two, one and three years old respectively. Therefore, it can be concluded that: firstly, the parents had a good level of awareness of the child's development which enabled them to recognise that their child might be different or delayed in his or her development.

Secondly, these findings could also be associated with the parent's observations on *aspect of the child's behaviour that the parents found that make the child*

*different*. Almost all of the responses demonstrated that the child is different from other children. The parents express these differences as including the following symptoms: limited eye contact; limited babbling; having a very quiet child; hand flapping; language delay; apparent deafness because the child does not respond to his or her name; limited awareness of what is going on around him or her; attention deficit hyperactivity; developmental delay and psychological disorders. In addition to that, this could be linked to the previous illustration of the parental educational level, where almost half of the study sample were highly educated parents which might affect their awareness level and ability to recognise these differences.

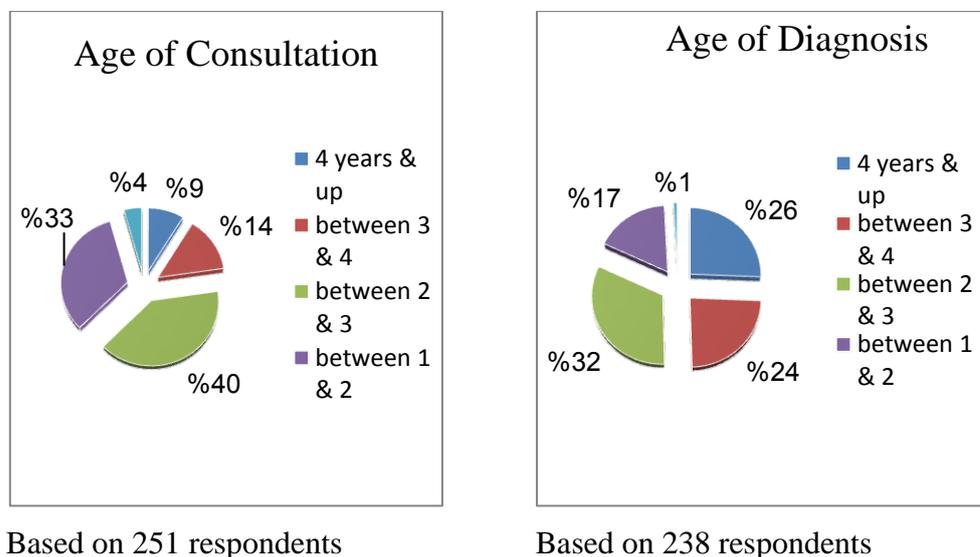
Figure 16 Difference Recognition



Figures based on 251 responses

### 5.2.1.9 The Diagnostic Process and the Child's Age of Diagnosis

Figure 17 Age of Consultation and Age of Diagnosis



The previous figure (17) illustrates the age when the parents sought a consultation and the age when the child was diagnosed. In the sample concerning the 2-3 year old age group, 40% of the parents sought a professional's help but only 32% of the children received the diagnosis at the same age. Furthermore, 35% of the parents looked for a diagnosis when the child was between 1 and 2 years old and only 17% of those children were diagnosed at that age. In the sample, 26% of the children were diagnosed when they were four years or older, however, only 9% of them consulted a professional at this older age. This might also be linked to the previously illustrated point regarding the parents' ability to observe the differences of their child's development from an early age.

Another way to interpret the data is that there is no significant time difference between the first time the specialists were consulted and when the child was diagnosed. The majority of the children were diagnosed between the ages of 2 and 5 years old, and this can be seen from the following percentages: 32% of the study sample reported that their child was diagnosed between 2 and 3 years old, followed by 26% over the age of 4 and 24% between 3 and 4 years old. Indeed, the difference between these percentages is minimal. In general, these figures are

consistent with the current literature on the age of diagnosis, where the detection of autism spectrum disorder signs before the age of three has become a trend in current research within the autism field (Matson, 2011). Moreover, this might also give an indication that autism diagnostic services in Saudi Arabia are developing and keeping abreast of current developments in this area.

### **5.2.2 The Importance of Demographical Information to the Current Study**

The current study results might help in suggesting a framework to establish a parental training programme that fits the family's needs within the context of the Saudi culture. Therefore, part of the process of developing such services is making sense of the family demographics. As illustrated previously in Chapter four, understanding the learner's<sup>40</sup> characteristics is critical in designing and providing a training programme in general. Within this study there are two different samples represented, a selected and a general sample, and comparing the demographical characteristics of both of them would help in drawing a clearer picture of the types of learners that would be served through this kind of training programme. Taking that into consideration the current programme aims to look for the general parental needs that could be addressed as early as possible whilst acknowledging that each case is unique and has individual needs that should be met through other services. Therefore, the first part of the questionnaire focused on obtaining the demographical information which would help in fulfilling the current study aim. Following is an illustration of the link between each demographical question with the current study aim.

'A parental training programme' would suggest that both the mother and the father, or at least one parent or caregiver, might participate in the training programme. From a professional perspective, both the mother and the father have an equally important role to play in the child's development; however, developing such a mixed gender training programme should consider the sensitivity of the Saudi culture in which the current study was conducted. One of the research questions is to identify *how might the parental training programme*

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<sup>40</sup> 'parents of individuals with autism in the current study'

*be run?* Accordingly, several questions arise at this point in order to count the specificity of the Saudi society that needs to be taken into consideration. Here are a few examples:

Based on both results obtained and illustrated previously, in which 79% of the questionnaires were completed by the mothers, it was understood that in the Saudi culture it is expected that the child is the mother's responsibility. Therefore, would the father be willing to attend such a course? If so, when providing the course, would it be a mixed gender course or alternatively separated gender courses, one for the males and another for the females. In the case of a separated gender course, would the female instructor be accepted by the male participants?

According to Saudi culture a segregated course would be the preferred case. Moreover, in both a mixed gender course and a male course instructed by female authorities, permission is required to run such a course, and obtaining the authority's permission to conduct a mixed gender course or even a separate course provided to males by a female instructor could take a long time, or might be refused for a researcher not working for any governmental sector.

Indeed, meeting all of these previously discussed issues that relate to cultural specificity proved to be impossible for the current study due to time limitations, where obtaining permission might be time consuming. Thus, other studies needed to be undertaken to investigate the possibilities of conducting a mixed gender course and its acceptance by both female and male participants, as this might be one of the barriers faced in providing such parental training within the Saudi context. Subsequently, the decision was made that the current training programme will only be provided for the mothers. This decision was supported by the parents' responses when asked, *questionnaires completed by whom?*, for which 79% of the questionnaires had been completed by the mothers. Therefore, the participants' responses to this question helped with the decision that the participants would be mainly the mothers, which would solve the previous dilemma of determining the gender of the training participants, as gender and

gender segregation are one of the controversial issues within the Saudi culture that is shaped by both Arabic traditions and Islamic Sharia law.

There are other demographical issues that would clarify the factors which need to be considered in developing a parental training programme. For example, *the child's age* helped with investigating the amount and kinds of services that should be provided to the different age groups, including those who are between two and six years old in the study sample group. This is because knowing the amount as well as the type of services, directed the steps that the current study has undertaken. Indeed, 35% (n=77) of the respondents showed that the age group of three to five years old are receiving centre-based services. However, a closer examination of the results also shows that only 20 (n=20) of those children are between three and four years old. Linking this to *the age of diagnosis* where 56% of the sample were diagnosed between 2 and 4 years old, one can anticipate that early intervention centre-based services that are currently being provided to the age group of 3 to 5 year olds, are minimal compared to the percentage for this diagnosed age group as presented previously. Thus, it seems that the children do not receive the service once they are diagnosed, but they might receive it later, after the age of four, according to the obtained information from the current study sample. Therefore, providing a parental training course that would lead to an early intervention home-based programme would be a service that is required in order to accommodate the recently diagnosed children and their parents as early as possible, and to compensate for the current shortages in early intervention services in Saudi Arabia.

*The child's gender* might also be an essential indication in this study because the child gender preference of males over females still exists within the Saudi culture. The cultural understanding behind this is that the boy is expected to be the man of the family who would hold the responsibility of his father. Indeed, if this is linked to *the child's sequence* or *the number of children* in the family the case would be read differently. For instance, if the child is a boy and the first in the family, or if the child is the only boy in the family, regardless of his position in the sequence, this would make a huge difference when the parents deal with

and face the idea that he has autism. Consequently, an awareness of such an understanding of the gender differences and preferences is critical because the parental reactions and actions in looking for solutions in facing their child's difficulties might be affected, either consciously or unconsciously, with the view that they hold in their mind which is inherited from the Saudi culture.

In addition to *the number of children* in the family, *the number of children with a difficulty* and *the kinds of difficulty being faced*, there are other factors that one should be aware of when developing a parental training programme. The previous factors indicate the amount of mental, physical and economic load on the family. Part of the training programme would focus on dealing with these different loads, which might be a result of having a child with autism in the family. For example, based on the results obtained from the questionnaires 7% of the respondents reported having another child with autism and or any other disability within the family. Therefore, the way that the parents approach the child's problem would be affected by the previously illustrated factors, because the greater the number of children in the family, the greater the mental, physical and economic load would be on the family. Moreover, dealing with one child with autism would be different from dealing with two children having autism or any other kind of disability. Thus, understanding the family's needs at this level is essential because the aim of the training programme is to accommodate the different parental needs and to offer practical and easy to implement strategies.

*The mothers' and fathers' level of education* is another critical factor that needed to be considered in providing the training services. The current questionnaires' findings demonstrated that the majority of the sample were educated parents, although various parental educational levels might coexist. Therefore, identifying the appropriate approach which would aim to meet this variation is essential. Finding this approach and devising an easy to access training course is not an easy task. It required a lot of effort to find a commonality between the parent's needs and to benefit from the advantage of having well educated parents attending the course in supporting the other parents who are less educated.

*The fathers' and mothers' occupations* would help in anticipating the family's socio-economic level. Indeed, the socio-economic level has a significant impact on the types of services that the family could provide to their child, especially if one considers that the current public services provided to individuals with autism and their family in Saudi Arabia are very limited. As a result, offering expensive private services would be an alternative. However, affording such services is not accessible to all of the families. Therefore, being aware of the financial barriers that might face the parents is essential as this might create both financial and emotional problems to the family not able to help the child and offer him/her the support that s/he needs. Such feelings might affect the way that the parents approach their child's problem.

Finally, the last of the four questions covered *the diagnostic process*, starting from the suspicion, moving to the consultation and ending with receiving the diagnosis. The importance of this information would highlight the gap between the suspicion and the consultation time, and the consultation and the diagnosis, and then linking them to the child's current age. Having said that, the questionnaire sample recruited were the parents of children who were currently receiving the intervention services. Identifying the gap in the process would help in anticipating the time that parents might spend until their child receives the right intervention services. As retrieved from the previous results, those who received intervention services when they are under four years old when compared to the age of diagnosis, were 7% of the questionnaire's sample. This would suggest that providing a parental training programme would help in filling this gap. This is because the first five years of the child's life are essential for enhancing his/her growth in general. Therefore, making the best use of this critical time is essential for all children, but especially for those with special needs such as autism. Thus, examining the family demographics and their relation to the aim of the current study, and then moving to the diagnostic process and the age where the parents' journey with autism would start. The focus of attention within the next two parts of the questionnaire was directed towards the parents' actions and needs in confronting the difficulties of autism.

### **5.2.3 Part Two and Part Three: The Difficulties Facing the Child and the Parents**

These two parts of the questionnaire were designed to cover different aspects of the parental needs and actions in relation to their child's difficulties. Part two consisted of eight 'filter type questions' where answering one question would lead to more details related to the same question. For example, when the parents were asked *if they spend more time with the child with autism than the other children in the family?*, a further two related questions were asked in order to clarify *the length of time* and *kind of activities* that would be practiced during that time. Getting this extra information would help in anticipating the kind of parent-child interactions that might exist and the quality of the time that had been spent with the child. In answering these interrelated questions the result demonstrated that 74.7% of the study sample spend more time with the child with autism with 62.5% spending more than three hours a day with the child and some saying they spent the whole day. Figure (18) represent these results. In terms of average time and length the parent's spend with the child linked to the kind of activities the child was exposed to during this time, Table (14) summarises the activities that were reported by the parents, sequenced by the most exercised activities.

Figure 18 Average Time and Length that the Parents spend with the Child

Based on 251 responses

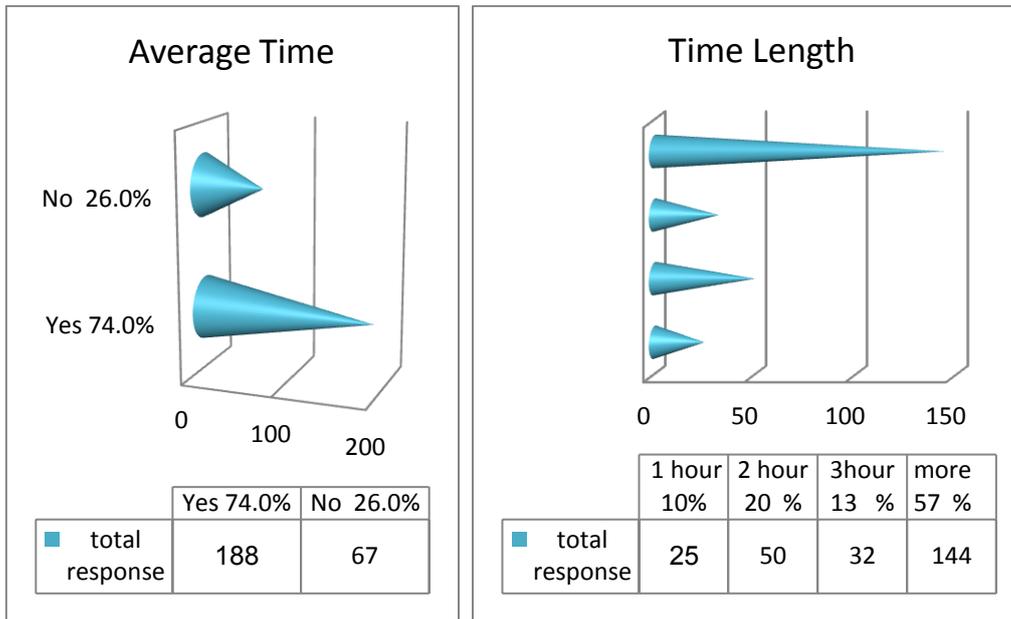


Table 12 Type of Activities Spent with the Child

Based on 251 respondents

Activities	Response Percentage	Response Total
Talking to my child	76%	196
Keeping my child safe	73.3%	188
Playing with this child	72.9%	187
Developing self help skills	67.4%	174
Watching TV with my child	67.4%	174
Singing with my child	51.6%	133
Training for independence	48.8%	126
Other activities	28.7%	74
Reading to my child	19.4	50

Regardless of the fact that 74% of the parents' responses indicated that they spend more time with the child with autism, their responses to the kind of activities applied during that time indicated some inconsistent responses. For instance, 76% reported that *talking with the child* is one of the most practiced activities. Indeed, this response with such a high percentage is quite confusing because communicating with others is one of the major difficulties that an individual with autism encounters. Therefore, how would the parents be able to incite and maintain a conversation successfully with the child, where communication is one of the major difficulties for him/her. The second highest indication was that 73% of the respondents reported that they spend that time *keeping my child safe*, which raises a question over the quality of the time that the parents spend with their children, because this might suggest the idea that the parents are being protective. Playing with this child was the third highest response, where 72% of the sample reported that they spend their time playing with the child. This might also lead one to think about the kinds of activities that might be taking place alongside the issue of keeping the child safe. This was followed by 67% of the respondents *developing self-skills*, and equal to that in terms of percentage was *watching T.V with my child*. *Singing with my child* and *training for independence* were also activities reported by the parents with quite high percentages, 51% and 48% respectively. The smallest percentage was 19% of the sample where *reading to my child* was their response.

Interpreting these previously illustrated results could afford different explanations. The activities reported by the parents during the time spent with the child often varied. Indeed, most of the respondents chose more than one option in answer to this question. However, some of these responses were conflicting as stated earlier, especially when comparing them to the parents' answers to the *other activities* options. Several other activities were illustrated by the parents. They express these activities as including the following: learning skills such as reading, writing, computing or doing homework; entertainment such as colouring, drawing, pretend play or going for a walk; physical activities like swimming and cycling; and social activities including integrating with other children and tickling and cuddling. Within the context of the Saudi culture, what

the parents' express freely in the other activities option reflects the real activities that they would practice with their children more than the other suggested options within this question. This does not mean that they do not also apply them but that they may not be their favourites. Another explanation might be expected from the parents' responses to the time that they spend with the child and the activities that they practice, is that time is not a problem to the caretaker, as according to their replies, 74% reported they spend more time with the child. However, one can anticipate that making the best use of the time and planning adequate activities that serves the specific aim and goal might be limited.

Another question that is aimed at examining other aspects of the family life that is related to both the parent's and the child's difficulties was *do other siblings play or interact with the child, if yes provide examples?*, or in the case of no, *why do you think this happened?* On one hand, 75% of the respondents reported 'Yes', and they express these examples as including the following: physical activities, such as running, swimming, cycling, dancing, and fighting; social activities like pretend play, playing with toys and play that is emotional in nature, such as tickling and cuddling. Indeed, these could be linked to 'other activities' as previously illustrated and reported by the parents that are performed while they are spending time with the child with autism. The parent's responses to both questions are similar in terms of the kind of activities they perform with the child and the kind of activities the siblings perform with the child. Thus, this makes one presume that this reflects a clear picture about the family and child interaction and the kind of activities the child might be exposed to in a natural setting.

On the other hand, 25% of the respondents replied with 'No' to answer this question. They referred to the lack or limitation of the child's siblings' interaction for several reasons, most of which reflect the child's difficulties in his/her limited social ability; these include: the child is unable to follow peers and siblings to play; the child's inability to speak; the child's desire to be alone; or the child's aggressiveness. Other reasons might include the child's age as being older than

his/her siblings, and that the other children rejected the child with autism or do not like his/her games or way of playing.

*Do other siblings take responsibility of the child; provide example?* In the case of a No answer, they were asked *why do you think this happened?* These two queries examined another situation that would reflect the child with autism and the family's interaction in a natural setting. Of the total respondents, 70% reported that the siblings do take responsibility of the child with autism. Examples that were reported by the parents varied and could be classified under general categories these include: providing daily care directly or by teaching its skills to the child, such as feeding, dressing, cleaning and studying; providing moral support, such as keeping a child safe inside and outside of the home, helping him/her to express his/her needs and feelings and considering the child's special needs. The rest of the respondents who answered this question with 'No' explained the reasons why the siblings are not involved in taking responsibility of the child with autism with the following reasons: the siblings are too young to hold any responsibility, the siblings are jealous of the child with autism, the siblings have a disability themselves, the siblings find it difficult to understand the needs of the child with autism or the siblings are busy in their study, so a nanny is taking a responsibility of the child.

Indeed, identifying this information about the siblings' role in the child with autism is very important to the current study as this might help in drawing a clear image and identifying any commonality that Saudi families share which might reflect the specific aspect of the Saudi culture in which brothers and sisters are expected to take care of their younger siblings or those who are in need, even in the long term. An interpretation of the previously demonstrated findings shows that the siblings' involvement with the child with autism is clearly presented. The idea of a family member taking responsibility and their expected role has been discussed and clarified previously in Chapter (2) regarding the Saudi context, and the reader should refer to that chapter for more information.

The parents gave diverse replies when asked *what kinds of skills do you want your child to acquire at this stage?* The following is a list of skills that the parents were concerned to teach to their children. It is displayed starting from the most to the least popular according to the parents replies:

- A self-care skill was one of the mothers' priorities to teach their children.
- Speech and verbal and non-verbal communication skills.
- Attention to and responding to instructions.
- The acquisition of acceptable social behaviours.
- The acquisition of academic skills (reading, writing, counting).
- Acquire play skills.
- Use of the computer.
- Avoid danger.
- Skill proficiency in writing with a pen.
- Be able to control hyperactivity.
- Memorising the Qur'an.
- Distinguish the types of money and acquire the skill to use them while shopping.
- Self-control and not to harm self or others.
- The use of a mobile phone.
- Swimming.
- Recognising family members.
- The development of cognitive ability.

The skills that the parents were concerned about could be linked to difficulties in autism and classified under the triad of impairments umbrella (social and emotional, language and communication and flexibility of thought and imagination). For instance, speech and verbal and non-verbal communication skills, attention to and responding to instructions could be classified under the language and communication impairment, whereas the acquisition of acceptable social behaviours, the ability to self-control and not to harm self or others, recognising family members and acquiring play skills would be classified under social and emotional impairments. Other skills, such as a self-care skill, the acquisition of academic skills and the use of the computer, etc., would be

categorized under the flexibility of thought and imagination impairment. Another interpretation that could be read from the parents' responses to this question is that the child's age might determine the kind of skills the parents want the child to acquire, such as the use of a mobile phone and distinguishing money and acquiring the skill to use them while shopping. Regardless, of the questionnaire sample being diverse for the child's age and for those children receiving interventions through a centre, skills associated with the autism triad of impairments is still at the top of the problematic list for the parents.

The parents were asked *How do you educate yourself and your family about autism?* The quantitative data shows that they use different sources to obtain information about autism, Table 15 below provides the most frequently selected resources, considering that the parents have the flexibility to choose more than one source. Indeed, the majority of parents (70.03%, n=180) in responding, stated that they access the internet to acquire knowledge about autism. T.V. and books were reported to have an almost similar percentage (63.7 %, n=163 and 60.2%, n=154 respectively) in terms of the source that the parents might consult to educate themselves about autism. According to the respondents, paediatricians (45.7%, n=117) seems to be the professionals that are most consulted by the parents in order to obtain knowledge about autism, followed by psychologists (38.3%, n=98), educationalists (29.7%, n=76), and finally social workers (23.85%, n=61). Speculatively, this could be linked to the diagnostic process where a paediatrician is expected to be the first professional that is consulted, and then a referral to other professionals, such as psychologists, would be made by them. Educationalists and social workers might be seen as intervention providers; therefore, they came after the paediatricians and psychologists in terms of consultation. Newspapers (27.3%, n=70), magazines (20.3%, n=52) and radio (8.6%, n=22) were the least selected sources that the parents used to find out about autism. Other sources was an additional blank field and was included to allow the respondents the opportunity to list any item not stated, with 19.9% (n=51) of the respondents reporting that there are also other ways of obtaining information. The seven most frequently listed items were:

- Friends and family.
- Mothers of children with autism.
- Conferences, lectures and workshops.
- Leaflets and brochures.
- Pathologists.
- Autism Centres.
- Working in the field of autism.

Table 13 Source of Knowledge

Resource	Response Percentage	Response Total
Internet	70.03%	180
Books	63.7%	163
T.V.	60.2%	154
Paediatrician	45.7%	117
Psychologists	38.3%	98
Educationalist	29.7%	76
Newspapers	27.3%	70
Social worker	23.85	61
Magazines	20.3%	52
Other sources	19.9%	51
Radio	8.6%	22

Based on 251 respondents

Reading through these previous statistics might lead to different interpretations. The Internet is a handy tool which parents would be able to access at any time and get their questions answered quickly and free of charge. This might explain why it is ranked as the first source that the parents use to obtain knowledge about autism. Books and T.V. share a similar percentage in terms of the sources that the parents use. Both percentages were quite high, especially when compared to the percentage obtained by the professionals. This could be indicative of the level of education of the respondents, where the majority of the questionnaire sample were highly educated parents. Therefore, this might lead one to think that the parents independently search for ways to obtain the information they need about autism. Interestingly media, such as newspapers and magazines, also obtained a similar percentage to the professionals. This might be seen in the light of the shortages of qualified professionals within the autism domain, as it is a relatively

new field in Saudi Arabia. It was unexpected to find that the parents rated the professionals and the media at almost the same level in terms of the sources that parents might use to gain knowledge about autism, especially when one considers that the professionals would be the first station that the parents might consult during their journey with autism.

Indeed, looking at the other sources listed by the parents showed that there are other indirect sources that the parents might refer to in terms of finding out about autism; these include friends, family members and mothers of children with autism. Surprisingly, the other listed items, such as conferences, lectures and workshops, leaflets and brochures, pathologists, autism centres or working within the autism field, are representative of the professional domain. This might lead one to think about the participants understanding of the question, and whether they only view professionals within the context of face-to-face consultations.

The final question within the second part addressed the issues surrounding the most stressful part of the child's difficulties for the parents in the light of the autism triad of impairments. The vast majority, more than three quarters of the families (80.6%, n=208) replied that it was the *child's poor language and communication skills*. This was followed by (55.4%, n=143) the response of the *child's disruptive and bizarre behaviour*. Whereas, 47.7% (n=123) of the respondents answered that it was the *child's weak social awareness*. These findings present an interesting picture of the most stressful difficulties for the parents where language and communication skills seem to be a priority of the parents. In fact, this could be linked to the previously illustrated findings where the parental interest in language and communication skills is as an intervention priority.

Within the third part of the questionnaire a five point Likert scale, for the responses totally agree to totally disagree, was used. The parents were asked to rank thirteen statements that covered several aspects. Table (16) shows the parental responses to the statements in both percentage and numbers. By reading through these, the respondents have helped in generating a clearer view about

parental satisfaction and perspective on the professionals' role, the availability of the services and the family role. Thus, the first and second statements examined the professionals' role in terms of providing the parents with the information they need about the nature of autism and current available services for individuals with autism and their family. If one considers the degree of measurement between the two extreme levels of the responses strongly agree to strongly disagree, the responses to these statements were varied.

According to the parent's responses, it can be anticipated that doctors might provide information to the parents about autism and the available services, and so one might expect to get more information from their doctors. This could be generated from the parental reply where the highest percentage was for *agree* with 38% of responses to the first statement and 29% to the second statement. Therefore, there was no majority or average response to these statements. Indeed, this finding is consistent with the previously illustrated result. For example, calculating the percentages obtained from the strongly agree and agree responses in both the first and second statements (58% and 34% respectively), the result would be in a similar range to the previously obtained result, as the responses do not reflect the majority, in which the doctor obtained 45% for the resources that the parents use to obtain information about autism.

Looking at the participants' responses to the third, fourth and eighth statements that evaluate the parental awareness and their satisfaction of the current services revealed the following: on the one hand, parental awareness of educational programmes that are available to individuals with autism and their family is acceptable, based on the fact that 45% of the participants *agree* with the third statement, additionally, the sum of the *strongly agree* and *agree* answers reflected over half of the questionnaire sample, at 57%. For the fourth statement, 29% of the participants answered *do not know*, and this was the highest ratio in response to this statement. However, the calculation of the *strongly agree* and *agree* answers represented just under half of the sample, being 42.64%, whereas, the *do not know*, *disagree* and *strongly disagree* answers reflected 57.46% which represented over half of the participants. Thus, this result might suggest that

providing the parent with knowledge about the types of educational programmes for individuals with autism and the parental training programme is important. A reasonably large number of the participants' responses to both the third and fourth statements were split between the *do not know*, *disagrees* and *strongly disagrees* options.

On the other hand, the responses to the eighth statement showed that the parents are not satisfied with the currently available provided programmes for individuals with autism, shown by the vast majority of the study sample, with 85% of the answers being *do not know* (24%), *disagree* (33%) and (27%) *strongly disagree*. One interpretation of this could relate to either the limited number of currently available services or that people are not aware of the services' existence. Indeed, this result was supported by the participants' responses to statement six, where the parent was asked to evaluate the following phrase: *I think that offering a parental training course would help me to deal with and support my child in a professional way at home*. Both *strongly agree* (62%) and *agree* (30%) received the majority share of the study sample responses, which in total reflected 92%. This indicates the strong need for such training services to be developed and provided to the parents in Saudi Arabia.

Table 14 Survey of Autistic Knowledge

	Statement	Strongly agree	Agree	Do not know	Disagree	Strongly disagree
1	My doctor gave me a clear explanation about the nature of autism.	20.5% (52)	38.3% (97)	10.8% (26)	20.1% (51)	10.0% (25)
2	The information my doctor gave to me about available services to support individuals with autism has been sufficient.	15.56% (40)	29.1% (75)	14.4% (34)	24.1% (60)	16.7% (42)
3	I am aware of educational interventions that are available for children with autism.	12.79% (32)	45.3% (115)	22.4% (57)	12.4% (31)	6.98% (16)
4	I am aware of educational programmes that are available to parents to develop their support skills.	16.67% (42)	25.9% (64)	29.4% (75)	18.6% (47)	9.3% (23)
5	I am confident that I am able to help and educate my child.	18.22% (45)	28.6% (72)	34.8% (88)	14.3% (35)	3.88% (10)
6	I think that offering a parental training course would help me to deal with and support my child in a professional way at home.	62.4% (156)	30.6% (77)	5.43% (14)	0.78% (2)	0.78% (2)
7	I believe it is solely the role of the professional to provide intervention to my child.	20.93% (54)	28.2% (71)	16.2% (40)	30.2% (78)	4.26% (11)
8	Existing services that are currently provided to individuals with autism and their families are adequate and helpful.	2.72% (7)	12.0% (31)	24.1% (60)	33.8% (87)	27.2% (70)
9	I understand that there is no cure for autism.	13.67% (34)	23.0% (57)	33.5% (85)	17.9% (44)	11.7% (30)
10	I understand that my child will always need help and support to aid his/her development.	53.7% (135)	35.8% (90)	5.06% (12)	4.28% (11)	1.17% (3)
11	Living with a child with ASD is stressful to the mother	41.09% (104)	44.5% (113)	1.94% (5)	8.53% (20)	3.88% (10)
12	Living with a child with ASD is stressful to the father	32.17% (83)	42.6% (106)	9.69% (25)	10.8% (26)	4.65% (12)
13	Living with a child with ASD is stressful to the siblings	29.84% (77)	37.6% (95)	15.5% (36)	12.4% (31)	4.65% (12)

Based on 251 respondents

Statements number 5, 7, 10, 11, 12, and 13 within the third part of the questionnaire examined parental awareness of their role and feelings associated with this awareness. For example, statement 10 aimed to spotlight how parents perceive their role in terms of their ability to provide on-going support to their children. The parent responses showed that the parents have a very good understanding of their roles, as indicated by the *strongly agree* response to statement 10, which was 53% and the *agree* response which was 35%, totalling 88% of the sample. Nevertheless, the family trust in their ability to train the autistic child and for their needs to be supported and strengthened. This could be generated from the parents' responses to statements 5 and 7, where varied

responses were found. In the fifth statement the highest percentage found that 34% of parents *do not know* if they are able to educate their children. This was followed by 28% for *agree* and 18% for *strongly agree*, showing that they trust in their ability in teaching child with autism, whereas 14% and 3% of the respondents answered *disagree* and *strongly disagree* respectively.

The results obtained from statement 7 might also suggest a variation in the parents' belief in their ability to help their children with the role in child development. When the parent was asked whether *it is solely the professionals' role to provide intervention to the child* 30% of the respondents answered *disagree* whilst 28% answered *agree*. Both percentages are similar but when the *strongly agree* and *agree* responses are combined this suggests that 48% of the study sample see it as the professional's role. This could be linked to the previous illustration related to the parent's trust in their ability in teaching. Further, this could be linked to the statement (6) result which reflects the parent needs to receive training so that they would be able to help their children at home.

Statements 9, 11, 12, and 13 test the parents' understanding and expectation of the child's current and future difficulties and the feelings associated with that. Replies to phrase 9 demonstrated that the parents sense the extent of the child's difficulty but that might be mixed with a sense of hope in the presence of a simple solution. This was also clear from the variation in the responses where 33% replied *do not know*, which was the highest rate with an almost equal percentage to the other responses, *strongly agree* (13%), *agree* (23%), *disagree* (17%), and *strongly disagree* (11%). The responses to phrases 11, 12, and 13 confirm that the presence of the child with autism in the family is a pressure and a burden on all of the family members, even though this pressure varies in its degree, where the mother is the highest for expressing such stress, followed by the father and then the siblings. Also, this could be linked to the above demonstration of the expectation that it is the mother who is the primary caregiver for the child within the context of the Saudi culture.

#### 5.2.4 Summary of the Questionnaire Findings

Analysing the questionnaires revealed the following findings:

Part one:

- ✓ 79.1% of the questionnaires' respondents were mothers; therefore, the training programme would only be provided for the mothers as the primary care giver.
- ✓ The family demographics showed that medium-sized families of 3 to 4 children were in the majority, 49% of the sample were graduated mothers and fathers with various economic income.
- ✓ 7% of the sample have another child with autism and/or any other disability within the family.
- ✓ The majority of the children were diagnosed between the ages 2 and 5 years old.
- ✓ 7% of the questionnaire sample received intervention services when they were under four year old.

Part two:

- 74% of the parents were spending more time with the autistic child.
- 62.5% spend more than three hours a day with the autistic child.
- The quality of time and the diversity of activities practiced were conflicting and a source of wonder.
- 75% of the sample reported that the child with autism plays and interacts with siblings.
- 70% of respondents reported that the siblings do take responsibility of the child with autism.
- Language and communication skills, social and emotional skills, and thought flexibility and imagination skills were the skills that the parents were concerned to improve in their children.
- 70% of the sample use the Internet as the main source to obtain knowledge about autism.
- 60% of the parents rated T.V. higher than professionals as a source of obtaining knowledge.
- Some professionals and media were rated at almost the same level in terms of sources to gain knowledge about autism.

- 80% of the sample chose poor language and communication skills as the most stressful part of the child's difficulty, followed by bizarre behaviour and weak social awareness.

Part three:

- Parents' satisfaction of the professionals' role in terms of providing information about both the nature of autism and the available services did not reflect the majority of the responses.
- 45% of the participants agree on their awareness of current services but 85% of the answers reflected their dissatisfaction of the current services.
- 88% of the sample responses suggested that the parents have a very good understanding of their role.
- 34%, the highest percentage of the parents' responses, *do not know* if they are able to educate their children
- 92% of the responses were *strongly agree* and *agree* for the importance of offering parental training services.
- Parents understand the child's difficulties but this might be mixed with a sense of hope.
- The child with autism has an impact on all of the family members, where the mother has the highest result for facing stress, followed by the father and the siblings.

To conclude:

- A clearer picture of the types of learners that would be served through this kind of training programme was obtained from the demographical part of the study.
- On-going family needs were identified in terms of:
  - Available educational and information sources about autism for parents were limited.
  - Skills associated with the autism triad of impairments were still at the top of the parents' problematic list.

- Skills associated with time management, parental self-trust in helping a child and utilising the natural setting to enhance the child's ability need enhancement.

The next part of the descriptive is directed at analysing the interviews and then contrasting both the interviews and the questionnaire findings, with the aim of addressing the process of coding where the obtained data is organized in a way that would lead to the beginning of the conceptualization in accordance with the constrictive grounded theory approach.

### **5.3 Themes of Data Collection**

Unlike the questionnaire sample the interview sample was more specific with twenty of the mothers of the children who are newly diagnosed, have not been receiving services for more than six months and have no previous experience with autism, being interviewed. The aim was to identify both the mothers' and the children's specific needs at this early stage and then compare them to the general questionnaire sample results, in order to be able to find out the common and on-going needs and to use them to develop the parental training programme. The interviews were semi-structured in nature, however, a detailed description of the procedures of developing, sample recruiting and conducting have been discussed previously in the methodology chapter (see the prior discussion in Chapter 4). Indeed, in-depth, line-by-line reading, thinking, naming and memo writing were used to feed the analysing process. The aim was to generate as many codes as possible. As a result of this process, over 383 codes were identified. The next step was that the identified codes were grouped in categories according to their similarities and differences. As a result, 20 categories were generated. These 20 categories went through the same process of looking for relationships between them and this revealed identifying three core categories. These include difficulties, needs and actions. Thus, the process of categorising is central within the grounded theory approach. This step was followed by what is called theoretical coding where core categories are integrated and related to each other in a systematic way to establish the conceptualisation.

In this study, difficulties, needs and actions emerged as the core categories, and under each one were sub-categories that relate to the main one as follows:

- ❖ Difficulties :
  - Difficulties related to the child.
  - Difficulties related to the mothers.
  - Difficulties related to the services.
- ❖ Needs:
  - Needs for information.
  - Needs for skills.
  - Needs for emotional support.
- ❖ Actions:
  - Actions before getting the diagnosis.
  - Actions after getting the diagnosis.

Three approaches were employed to verify the categories from the qualitative data, as follows:

- The work, including the interviews, was conducted in Arabic. The work was transcribed by two skilled translators from a local Higher Education institution. The interface, with the data included subsequent to the translation and analysis, was provisionally checked by the translators as a means of gaining their reaction to the categorisation of the discourse.
- My doctoral colleagues at Brunel included two Saudi students who are well versed in discourse analysis and in particular thematic induction. Each of them agreed to read a sample of the transcripts (in Arabic) and they then examined the extent to which the path that I had constructed for the preliminary categorisation was auditable and made sense to them. This process enabled me to make some small adjustments to my provisional categories.
- My supervisors also read a sample of the translated transcripts and subsequently agreed with my system of classification and categories so derived.

These three main categories were analysed in the light of the current study questions in terms of (1) how might the parental training programme be developed? (2) What should the programme components comprise of? (3) How might the parental training programme be run? (4) What intervention strategies would be more effective and suitable to implement? As stated earlier the interviews were organized to cover the mothers' journey with autism, starting from the very beginning with the suspicions that the child might have a problem, through to the confirmation of the problem's existence and seeking help. Indeed, central to the grounded theory approach is identifying a core category that crystallises other categories and forms a pattern of relationships and meanings between them. This central idea could be seen through the following sequence: autism is a difficulty that creates other difficulties and needs and these would require actions to face these difficulties and fulfil the needs.

Initially, the intention was to analyse each theme under its heading. However, in practice this proved to be difficult because the human experience, that consists of a concern that is associated with feelings, and understanding that concern in which these feelings and understanding would lead an individual to act, is being investigated and analysed. Indeed, it is a reflection of the natural cyclic way of human thinking in facing life situations that confront individuals on a daily basis. Therefore, the headed sections devoted to analysing each section individually will not be applied; instead the analysis process will follow the cyclical route of the mothers' journey with autism as a difficulty that creates other difficulties and needs that are connected to the mothers' feelings which leads them to undertake a variety of actions as a result of that. The following discussion illustrates how these core themes were discovered and clarifies the relationship between them through a deep analysis of the interviews. Thus, the process of analysing how the individuals construct their understanding and actions would lead to the identification of the reasons behind their understanding and actions (Charmaz, 2006).

The main concern here is to generate a close understanding of the mothers' experiences in relation to having a child with autism. Indeed, autism as a

difficulty could be seen as central to the current investigation because autism creates other difficulties and needs to both the child and the mother. This was clear from the mothers' responses, where analysing the interviews revealed the identifying of three levels of difficulties that the mothers might encounter due to the fact that they have a child with autism. These are difficulties that emerge from the child him/herself having autism, difficulties that emerge from the mothers themselves and difficulties associated with the currently provided services. Indeed, these difficulties occur at interrelated levels, where looking at them collectively would help in understanding the magnitude of the suffering that the mothers might experience through their journey with autism. Thus, for organisational purposes the discussion is divided into two levels, the pre- and post- diagnosis stages.

### **5.3.1 Pre-diagnosis stage**

Asking the mothers to talk from memory about when they first realised or suspected that the child might have a problem was the starting point in all of the interviews. It was evident from the replies that there were difficulties that were associated with the child that led the mothers to suspect the existence of a problem. The mothers varied in terms of when and how they identified the child's difficulty. Those who suspected that there was a problem at an early age, regardless of what the problem was, said their suspicions were mainly based on problems associated with health issues, and these were different problems for each mother; epilepsy, premature birth, swallowing difficulties and sleeping problems, etc. Here are some health problems noticed by the mothers:

Interviewee (1) said: *'At the age of three months, she started having cramps in her hand or sometimes it was in her leg'*, and *'at the age of eight months it was clear that she had muscular spasms'*.

Interviewee (15) stated that *'When he was a baby, he couldn't swallow. I gave him liquids all the time, and he kept vomiting. His vomit was heavy. I went to the hospital and told them he couldn't swallow. They x-rayed his throat, but the result was that it was nothing and not to worry'*

Other mothers built their suspicions on symptoms such as limited eye contact, problems with fine motor skills, attention difficulty, limited language ability, limited social and communication ability, limited play skills, and restricted activities. These difficulties that could be associated primarily with autism are problems related to child development. The mothers usually noticed this at an advanced stage of the child's development.

Doubts expressed by interviewee (3) included *'When he was one year old he was sitting in one place: no movement, no attention, nothing to stimulate him'*.

Interviewee (17) said *'When she was a year and a half, I compared her with others her age; she wasn't like them. I would give her a cup of milk, but she couldn't hold it. I felt there was a problem'*.

The third group of mothers were told by other people, such as a family member, that the child might have a problem.

Interviewee (2) said that *'my uncle is a teacher and he had come across similar cases which made him suggest that my son might have autism. It was a shock for me; I would say to myself that there is no way is it autism; it must be a mental health problem because his nanny left'*.

Interviewee (10) expressed the time of suspicion in the following words: *'When he was three I noticed that he didn't talk. My relatives also asked why he wasn't talking. Also, when I worked in the autism centre, I witnessed things. I noticed that my child has the same signs'*.

The examples given above might indicate that a suspicion that a child might have a problem was common for the mothers, regardless of the kind of symptoms that were noticed or the child's age. In fact, the mothers varied in their ability to first, notice that the child is different in terms of his/her development from those who are of a similar age; second, consider the importance of such differences in the child's development. This may be due to several factors which reflect both the mothers' interpretation and the feelings towards her child's difficulties. For instance, having previous experience of children's development might make

some mothers more able to notice those differences, whereas a novice mother, where the child is their first, might have less experience in noticing the differences.

Interviewee (20) said *'I thought he was normal, but was shocked when visiting my family back home, and everyone noticed that he is developmentally delayed'*.

Later in the interview, she quoted a conversation between herself and her husband to exemplify their lack of experience in normal child development, where she said,

*'We were lying to ourselves that he is very smart, but we started to doubt ourselves. I am the youngest in my family and my husband is the youngest in his family as well and we did not doubt his late development because we do not have experience with children'*.

Contrastingly, interviewee (9) expressed her suspicion based on her experiences of having previous children.

She said, *'Since I gave birth to her, she was different from her siblings, starting with having sleeping problems, not being able to suck whilst breastfeeding and crying all the time. In fact she was tiring and needed extra support all the time'*

It was the same for interviewee (3), she said, *'I have a son who is older than him. There is always a comparison when you have previous experience'*

The interpretation of a child being different in terms of his/her development is another factor that might be associated with both the mothers' feelings and her understanding of the child's situation.

For example, interviewee (3) continued by saying *'I didn't really think too much about it, as I thought it was the child's nature which differs from one child to another and that this child was only different from his brother and that's it. His brother talked at a really late age, so I didn't really pay attention to it. I said to myself that his brother started to talk at a late age, so he would be the same, just like him.'*

Interviewee (20) said *'speech delay is hereditary in the family, so there is no need to worry.'*

Other factors might co-exist including: the mothers' worried or relaxed type of personality might affect dealing with health issues related to the child. Family circumstances such as having more than one child in the family or an unhealthy spouse relationship could be another factor that might limit the mothers' ability to be more aware and concerned about her child's case. For example, interviewee (13) expressed herself as follows:

*'I am a divorced mother with six children and do not know how and when I gave birth to them; I had governmental support because the father is an uncaring alcohol abuser and I have been on medication for thirteen years'*

The previous illustrations and the variation in the mothers realizing their child's problem at an early stage would suggest that a suspicion is a pre-diagnosis difficulty for the mothers. However, the mothers' actions were varied at this stage based on the feelings and understanding associated with their suspicions. These actions might include several aspects, like further consciousness, wariness and observation of the child's development and behaviour. Indeed, this was identified from the interviewees and was evident from the mothers' responses. For example, interviewee (15) said

*'Then I noticed that when I talked to him he never looked at me. I used to put him on my lap and hold his head like this, but it was in vain as he wouldn't look at me. He was one and a half at that time.'*

*'She was about two and a half years old, but she was not being her age. For example, concerning speech she only said: "mama", "papa" and "dada".'*

This was interviewee (17) observations on her child's development. From her speech it is clear that she was trying to compare her child to other children in terms of development. As noted above the mothers were concerned about the limitations and difficulties that became noticeable in their child's development. Consequently, looking for verification and finding answers that would clarify the

causes of the child's limitations were the resultant reactions. These reactions might create another obstacle that the mothers were trying to confront. For example, some mothers consulted the professionals first while others preferred to read and search the Internet themselves; some took both options to get their concerns met.

Interviewee (15) said *'I started to read about learning difficulties. I searched about visual communication on the Internet, and I started reading about it. I felt that my son has something wrong.'*

Interviewee (1) said *'I had my suspicions to be honest, but I didn't have any background knowledge of autism, so I started reading about it.'*

Interviewee (17) said *"When she was three I took her to the hospital. Also, I read about autism on the internet, and what concerned me was that she was hyperactive and not focused. I was torn between hyperactivity and autism because both had the same symptoms. I went back to the Internet to read about autism, the autism spectrum and hyperactivity, all which have a lot of symptoms."*

Interviewee (13) said that *'when I told the psychologists that I was following up with her regarding my concerns over my child and his inability to talk and to be toilet trained like others his age, and his nervous reactions, she suspected that he might be autistic. She advised me to get him diagnosed to make sure'*.

Indeed, suspicions led the mothers to seek help from the professionals and to get a clear diagnosis of their children's problems. The diagnostic process was a straight forward step for some of the mothers; for example, interviewees 1, 2, 5, 13, 18 and 19 mentioned that their children received the diagnosis from just two to four visits with the specialist. On the other hand getting the child diagnosed was complex and time consuming for others, where consulting the physicians was the starting point for quite a lot of the mothers. However, according to the mothers the answer was not always there. The mothers mentioned that the paediatricians usually refer the child to a child psychiatrist or psychiatric

specialist as they feel that the child needs further assessment to identify if s/he needs help. Indeed this might give an indication of the physicians' lack of awareness in relation to autistic characteristics. At this point the majority of the mothers went through long procedures of referrals and seeking a diagnosis from different professionals, such as psychiatrists, psychologists, pathologists, neurologists, educationalists, etc. This was the case for 12 out of the 20 interviewees. Moreover, a number of the mothers consulted more than one professional because the parents were not convinced with the diagnosis. For example, interviewee 4 emphasizes the disagreement between the professionals on the diagnosis.

She said that *'several diagnoses were given. At the same time psychologists told me it was autism or hyperactivity, the neurologist said it was epilepsy caused by extra neural impulses in the brain'*.

This goes to show that the role of the interdisciplinary diagnostic team rarely exists, which leads to the mother's confusion in terms of which diagnosis is real and best describes her child's difficulties.

Interviewee (15) exemplified this confusion in her interview when she said, *'to remain lost like this is a real problem. Seriously, when the parents are lost and don't know what to do it is a bigger problem than the child's problem, because the later you are in getting clarification of the situation, the bigger the problem'*

A diagnosis is usually associated with advice or a recommendation from the professional side. According to the mothers professional advice covered using medication, education or diet as a method of treatment. Physicians put children under medication based on the given diagnosis which then proved not to be the right decision in some cases, as 9 out of 20 of the interviewees mentioned such examples in their interviews.

For example, interviewee 17 said, *'At the beginning the doctor said it was brain electricity, and he gave us medication (Depakote) for about six months, and then he increased the dosage. It was one ml, and then he said that it should be increased by one ml every two weeks until it was three ml. Then, we had to give*

*her pills, I don't remember the name, which make her swell and caused her weight to increase.'*

Interviewee 6 said *'I did not notice any difference after using the medication apart from my child lost his hearing'*.

Interviewee (2) stated that *'In my opinion, the use of drugs is a waste of time and money; there is no advantage to using them'*.

The mothers reported different reasons behind using medication, for instance to control the child's behaviour, to improve concentration or to control seizures. Only one of the ten mothers who applied the drug treatment to their child reported that it was helpful in her child's case in terms of controlling the seizures, but not in improving any other of the limitations or the child's undesirable behaviour.

Almost all of the interviewees mentioned that finding a centre or school that provides educational intervention was further advice that the parents had received from the professionals as a result of the child being diagnosed with autism. For further clarification the mothers were asked if they had asked the doctors why the child should be exposed to such an intervention. In response to this question, it seems that some of the mothers did ask the professional and the reply was based on the idea that behavioural therapy is essential to children who have autism.

For instance, interviewee (11) said, *'I think they have a point because in the centre he learns self-care and how to be organized'*.

However, the vast majority of the mothers seem not to have enquired about the importance of exposing the child to educational intervention, and this was clear from their responses to this question.

For example, interviewee (3) said on one occasion that *'it is a psychological illness for which there is no cure'* and at another time *'it doesn't mean that we leave him like this; we have to proceed with him and treat him'*.

One can anticipate that any previous knowledge the mothers might already have could be the reason behind not asking the doctor about the importance of educational intervention for their children. Another reason could be that the mothers believe in professional expertise and knowledge. This was the case for some of the mothers.

For example, interviewee (7) said that *'the doctor emphasized that there is not anything better than educational treatment to train him; therefore, we sent him to the centre'*.

Based on the previous discussion, receiving the diagnosis is usually associated with the advice and recommendation provided by the professionals. The most common advice was to place a child under medication, suggesting educational intervention via specialized centres, where the names of recommended centres were sometimes given, suggesting a specific diet for the child and providing the parents with leaflets or information on implementing some intervention approaches at home.

Within the same context of examining the mothers' experiences of getting the diagnosis and difficulties associated with that period, the professionals' practice could be seen as one of the problematic issues for the mothers. Both satisfaction and dissatisfaction of the practices of the professionals were reported by all of the mothers. There was no one interviewee who was fully satisfied and happy with all of the professionals that she had come across; however, there was no agreement between the mothers over the specified professional's name or the services provider in terms of good practice and helpfulness. Thus, the mothers reported several examples of their happiness and satisfaction with some professionals they had encountered in terms of their expertise and support.

For example, interviewee (6) reported that *'at first I was lost but I felt more settled with my doctors' support'*.

Interviewee (15) said *'There was a doctor called Dr. O. -may God bless her- she gave me a program called "Portage" which she told me to apply to Osama, to show me how to teach him how to make sentences. It was really beneficial. She was the only one'*.

On the contrary, quite a lot of the mothers were not happy with the professionals' performance or their recommendations and in some instances they were not happy with the way that they had reported the diagnosis to the mothers.

For instance, interviewee (3) criticized one of the professionals that she had consulted. *'He did the autism test, which is called "CARS". He asked me too many questions, but the problem was that he wrote in his report: "severe autism". This word "severe" upset me. How could he say severe and my child is so young? And he only sat with him once!'*

Another example of a mother's dissatisfaction with the professional practices was as interviewee (5) said; *'I went there twice. She doesn't tell the mother everything. I want her to confront me with what is wrong with him. She only says "it will be all right" and "relax".'*

The mother's view in this case might exemplify the limited information that is given by the professionals to the mothers regarding their children's difficulties. This view was expressed on several occasions in interviews 7, 8, 11, 13, 15, 17 and 18. Interviewee (4) commented that

*'When I asked the doctor what autism means he said it is almost like paralysis of the brain cells. His interpretation of the meaning of autism was surprising to me. I felt that he did not have any confidence in the possibility of hope in the treatment when he said: hope is in God's hand. At that point I felt that all doors had closed in my face'.*

Interviewee (13) also commented *'what they care about is that the child doesn't ruin something in the clinic.'*

Within the same context of the professional's practice, interviewees 1, 8, 11 and 15 said that finding qualified trusted professionals is not easy and when one is found, the cost is very expensive; this was mentioned by ten of the twenty interviewees.

Moreover, interviewee (11) put forward the idea that *'some of the professionals use their specialties as a business and play on the parents' dreams of helping their children'.*

Interviewees 3, 8, 15 and 20 had a similar idea about business and professionalism.

According to interviewee (20), *'Professionals are supposed to be supportive and helpful but this is not usually the case. It turns out to be a business which is disappointing'*.

Interviewees 3, 11 and 15 think that professionals in the Arab world are limited in their knowledge and expertise related to autism. Moreover, they do not have the desire and motivation to study and investigate within this field compared to professionals in the rest of the world.

One of them said, *'The doctors in the Arab world are not up-to-date with the fact that this protocol called the "DAN" protocol is being applied abroad. In the Arab world, they don't want you to know about new things'*.

Whereas another one thinks that *'Scientists are not interested in investigating the causes of autism and finding a treatment for it as it has been impossible until now; there is no cure and the causes are unknown.'*

The previous discussion exemplifies the difficulties that the mothers might confront in relation to the professional practices at the stage of getting their child diagnosed. The common issues amongst them are not being satisfactorily addressed by the professionals and they are looking for something more.

For example interviewee (1) reported *'Having a child like this is a really big problem. You don't know what your child's situation is. You can't find doctors or a treatment for her case'*.

Another mother said, *'What I wanted from the doctors when they diagnosed our children was to sit with them and ask them to see how they communicate in order to make a judgment'*

The previous comment might lead one to conclude that the mothers would be happy when they received the information and practical guidance on how they could help their children. On the other hand, they complained about the

professionals' lack of an explanation, that they are limited in their expertise and ethical practice. The mothers' illustration of the professionals in their conversations emphasized the importance of the role that the professionals play in terms of providing the parent with sufficient information and support at both the pre- and post- diagnosis stages, because both stages are considered to be difficult periods for the parent. Indeed, it is just the beginning for the mothers to get their concerns and questions over their loved ones answered; however, the answers might not be so comforting since it is a mothers' natural desire to have a normal and healthy child.

One interviewee expressed her feelings at the result of the diagnosis in the following words *'You know what trauma is but you don't expect it. You picture a life for your child where he is normal and that he will learn. All of a sudden, you see this destroyed.'*

The level of difficulty is now moving to another direction, a direction that is connected to the feelings where the mothers are experiencing a mixture of hard and complicated feelings, such as denial, anxiety, ignorance, self-blame, weariness, acceptance and hope, etc. This, indeed, could be seen as a difficulty that emerges from the mothers' themselves.

For example, interviewee (2) described that *'I was crying and blaming myself. It is my fault; I left my son with the nanny. She must have put black magic on him'*.

Interviewee (8) said, *'Of course, I was shocked. Then, I was in denial telling myself that nothing was wrong with my daughter, she will be fine and she will learn over time. Eventually, I had to accept the reality that she has autism'*.

Interviewee (10) expressed, *'I was so afraid...I cried... I was so sad. There is no mother in the world who does not wish for her child to be normal. It is difficult for us to have something like this, especially as in our society most of the people don't know what autism is. I used to work in an autism centre, so people have asked me about the meaning of autism. I was sad, but I will never give up. I would go to the end of the world if I knew there would be a cure for it.'*

The previous examples reflect the complex feelings that the mothers might experience in such a situation and indeed, part of their difficulties is to have these mixed feelings of believing and not believing at the same time. The emerging feelings connected to a child being diagnosed with autism would create emotional needs which in turn call for emotional support so that the mothers would be able to deal with those negative feelings. These emotional needs were expressed by the mothers to exemplify the stage after getting the diagnosis.

For example Interviewee (4) said *'I do feel stressed, and I cry especially if I felt that he wanted something and I do not understand him'*.

Similarly Interviewee (13) stated that *'I had a bad temper do not have the desire to do anything'*.

Interviewee (8) expressed that *'After getting the diagnosis, there was always a tense debate and a disagreement between me and my husband over the way we should deal with the problem'*.

Both interviewees 11 and 5 wished that their child had died so that they would be relieved from the stressful life the children might face due to their difficulties.

Interviewee (5) continued to say *'After they told me my son had autism, I felt lost, stupid, and did not know what to do. As a result, I became depressed and am still under medication until now'*.

Indeed, from a close examination of the mothers' experiences of getting their child diagnosed, one can anticipate that the previous examples of the difficult feelings that the mothers might experience would lead them to take further action by finding solutions to their children's problems.

Interviewee (8) commented on that by saying *'After the denial stage, I went through self-blaming. After that, I accepted it. Now all that I am thinking about is how to help her'*.

Interviewee (4) said *'I wished that I had someone who could provide me with support and help so that I could help my child'*.

At the pre-diagnosis stage the mothers' concern was to find an answer for their children's developmental delay. Consequently, looking for a solution would be the next stage.

### **5.3.2 Post-diagnosis stage**

At this point, the mothers have moved to the post-diagnosis stage where the main concern is to help her child. This stage is a difficult period for the mothers; its complexities sometimes emerge from the mother's feelings, the mother's expectations, the mother's understandings, the service's existence and its quality and many other factors. Indeed examining the feelings of their understandings and the actions separately, aimed to identify the difficulties that the mothers may encounter at the post-diagnosis period. Subsequently, the parental training programme that is intended to be developed based on the parental needs would consider these difficulties and try to provide the mothers with support that might help in reducing the effects of these difficulties on them. Thus, the following paragraphs will continue examining the difficulties that the mothers might encounter at the post-diagnosis stage that have been identified from the interviews with the mothers. Part of the interview's questions focused on asking the mothers about the child's difficulties and how they tackle them and feel about these difficulties, as this would help in examining the mothers' practices and to identify strengths and weakness within their practices which would feed the skills that need to be covered into the training programme. Analysing this part of the interviews identified both the needs that are commonly shared between the mothers and the specific needs that are related to the individual cases. The common needs that were identified within this part of the interview were related to the child's limited abilities and undesirable exhibited behaviours. Considering that, one of the study's aims is to identify the common needs between the mothers; therefore, only these common needs are discussed and highlighted. The following paragraph examines the mothers' efforts to help their children in the light of factors that might affect their ways of dealing with the child's problem of having autism.

#### **5.3.2.1 Difficulties Associated with the Mother**

As stated earlier and following the human way of thinking when it is confronted with any situation is that how a person understands and has feelings about the

situation affects his/her actions towards it (Alkeedar, 2006). Therefore, the mothers' actions in confronting their children's difficulties were analysed based on the previous philosophy of human thinking. All of the mothers were asked to define *what does autism mean to them* and *what the causes of autism are*. The aim was to examine their understanding of autism as a main difficulty that creates further obstacles. The majority of the mothers had some idea about autism to a certain extent. However, a clear notion of autism, the characteristics of autism and its causes is very limited and is sometimes mixed up with other types of disability. The following are some examples of the mothers' definition or understanding of autism.

One mother sees autism as a *'lack of communication and socialisation'*. Interviewee (12) defined autism as a *'developmental delay in terms of the child's ability to talk, think, and play'*. An additional definition provided by interviewee (10) is that *'the child has a normal appearance with a limited mental ability; lack of eye contact and the ability to socialise are the child's main problems'*.

The previous definitions might indicate that some of the mothers' understandings of autism have highlighted the major problems that are related to autism as a developmental delay that affects the child's ability to communicate and socialise effectively. Contrary to this, some of the mothers' responses to the same question might give an indication of their limited knowledge about what autism is. Some of the mothers see autism as a psychological disorder. Others think of autism as an incurable disease. A couple of the mothers see autism as madness. Moreover, learning difficulties, hyperactivity, and attention deficit were also mentioned by some of the mothers to define autism.

For instance, interviewee (17) said on one occasion that autism is *'a failure to concentrate. She doesn't concentrate'*. *She doesn't have any communication with others as it is so difficult'*.

On another occasion she mentioned that *'She is not handicapped; I thought that she doesn't belong to the groups of special needs children. I felt that I should search for some information for her. I searched the Internet about autism. I thought it was a disease. I didn't know anything about it'*.

The previous examples indicate that there is confusion over the notion of autism for some of the mothers.

Interviewee (14) said, *‘Autism means that the child will be dependent on others forever and that the child needs to be supported for feeding, dressing and all skills in general’*.

Interviewee (19) described autism as madness. She said, *‘I do not know what autism is. To tell you the truth I feel that it is like madness. You might find your child laughing alone and without any reason’*.

In terms of the causes of autism, the mothers also have different ideas. Some of them related autism to health issues while other ideas reflect the mothers’ interpretation of autism causes. Some of these causes might be applied to individual cases, especially those related to health issues, as the mothers expect that having such health problems might lead to the development of autism. These causes include:

- premature delivery
- shortages of oxygen at the time of being in labour
- the mothers or fathers being on medication that might affect the child during the pregnancy
- the mother being under mental pressure during pregnancy might also affect the child’s development
- it is hereditary, as the father has some of the same characteristics that the child has, and he and the spouse are relatives
- environmental deprivation in terms of the limited social experiences that the child is exposed to
- heavy minerals, mercury and a sensitivity to gluten and casein
- genetic causes
- unknown causes
- other factors, according to the mothers, include the envious eye, black magic or evil spirits.

Similar to the mothers’ understanding of autism, one can anticipate that their knowledge about the causes of autism seems to be limited and unclear, because almost all of the mothers mentioned more than one reason that might be the cause of autism. Moreover, none of them were clear about what causes autism as most

of their responses were based on speculation. The following are some examples of the mothers' expectations of the causes of autism:

- Interviewee 4 assumed that her child's situation might be due to oxygen shortages at the time of labour, because the parents are relatives, or because the father is on medication. Providing three different reasons might exemplify the mother's uncertainty about the causes of autism.
- Interviewees 3, 19 and 20 believe that it is a hereditary issue, as children inherit their characteristics from their parents. They observed that the child and the father share some characteristics in terms of temperament and the limited ability to socialise. Added to that they reported that speech delay was common in the father's family.
- Environmental deprivation in terms of the limited social experiences that the child is exposed to because of being the only child in the family were reasons mentioned by interviewees 6, 8, 10, 14, 17 and 20.
- Interviewees 7, 9, 12 and 16 believe that the envious eye, black magic or evil spirits might be the cause.

Interviewee (7) said *'as the child is very handsome and different from his siblings, someone might have given him 'that look''*.

Interviewee (16) believes in evil spirits and she said that *'most autism cases are caused by evil spirits'*. The mother had been told this by the Sheikh spiritual healer that she used to visit.

- Interviewee (11) supposes that heavy minerals, mercury and sensitivity to gluten and casein are the main causes of autism.

She said, *'removing these heavy minerals is essential so that the child could function normally, as leaving them in the child's body affects the brain'*.

The interviewees within this study were the mothers of children newly diagnosed with autism so asking them about their source of information was essential, because such an enquiry would clarify the need for information sources based on the mothers' needs to be provided at a later stage of the training programme. The

mothers' responses showed that the knowledge that the mothers have about autism and its causes was mainly obtained from the Internet as their primary source of information. Although the majority of the mothers have access to the Internet, three of the mothers had only limited Internet access taking into consideration both their educational level and socio-economical level. The T.V. and leaflets were also mentioned in five cases (3, 4, 5, 7 and 9) as a source of information. Four of the mothers mentioned books as a resource to getting information; those were interviewees 1, 11, 15 and 17. Professionals as a source of information has been discussed and examined earlier within the diagnosis stage. Indeed, the previous examination of the professionals' role showed that the amount of information that had been given to the mothers by them was insufficient and minimal. This might explain why the mothers search the Internet as a main source, for further clarification and to obtain the information they need. Another reason might be that the Internet is a handy tool, easy to access at any time with no extra expense. Exchanging knowledge and experiences with other mothers of children with autism was mentioned as a source of information by interviewees 3, 8 and 11. Relatives and friends, according to 13 interviewees' reports, provided the mothers with some information about autism, especially in regard to autism services and types of treatment.

The mothers' understanding of their perception of autism and its causes were associated with both negative and positive feelings that had been expressed by the mothers on several occasions throughout the interviews. Therefore, the focus of attention will now be directed towards investigating the mothers' feelings, as these feelings have an impact on the mothers' decisions and actions, and similarly understanding that sometimes an individual's emotions can guide his/her behaviour, even with only a minimal understanding of the situation.

A sense of responsibility was one of the first feelings that was noticed throughout the interviews with the mothers, and on different occasions, starting from the suspicion of their child's problem, passing through identifying the problem and then to finding a solution to the problem. For example, in examining the mothers' responses when they were asked about what kind of support they would expect

that they could offer to their children at home, the answers to this question might exemplify both a sense of responsibility and how the mothers perceive their role in helping their children. The mothers' responses showed that they have a high sense of responsibility towards their children.

For instance, interviewee (12) said, *'I became very anxious because of the consciousness and sensitivity to my thoughts as a mother; my child is my problem - more than for the child himself, I want to treat him as quickly as possible.'*

However, confusion on how to address the child's problems was associated mostly with that sense of responsibility. The previous illustration of the mothers' efforts in applying and trying different treatment approaches is an example of both the mothers' sense of responsibility and their confusion in dealing with their children's problems by sometimes applying more than one intervention approach. It seems that they were aiming to confront the difficulties that the child is facing regardless of whether these approaches prove to be effective or not.

For instance, interviewee (8)'s opinion about trying any approach is, *'I would try everything that might help her and not deprive her of any hope of healing'*

Moreover, almost all the mothers reported that special attention was given to the child after receiving the diagnosis, where sometimes the attention for this child comes above other family members, such as the other children and the husband.

Interviewee (11) exemplified this, *'I spend most of my time with him; to be honest I do feel guilty because my other children need time as well.'*

This was similar to most interviewees as they see the child as a special case that needs more attention.

Interviewee (10) commented on that by saying, *'I have to pay attention to him as he needs attention. Now, almost all of my time is devoted for him.'*

Another example of the mothers' sense of responsibility towards their children was shown by them giving up almost all of their activities, hobbies and social life.

For example, interviewee (15) stated in her interview that *'I have artistic hobbies. He has taken me away from my hobbies, my priorities have changed'*.

Along with the sense of responsibility, some of the mothers see their role as providing the child with a proper education via special schools and centres.

Interviewee (9) said, *'I want to find a specialized autism centre for her so that she will learn. I do teach her at home but a special service would help her more'*.

Other mothers see acceptance and love as essential in their child's case.

Interviewee (13) reported, *'My duty is to be sympathetic, and to give this child more love, respect and care because these children are very sensitive'*.

Fortunately, only two mothers out of the twenty interviewees reported that they are feeling helpless and think that they are limited in their ability to help their children both materially and morally, even though they think they should do this.

Interviewee (5) said *'I feel that my hands are tied, with no money to offer proper treatment and no desire to do anything. I feel helpless'*.

The mothers' sense of responsibility was evident in all of the mothers' interviews. This sense of responsibility could be seen as one of the most positive feelings that the mothers hold towards their children.

Believing in (qaader) destiny is another positive feeling that was also expressed by the mothers. Almost all of the mothers believe in God's support even at this difficult time. They were using the word Alhamdulillah (which means Thank God) within most of their discussions. Several phrases expressed by the mothers showed their faith in God.

For example, one mother said *'God created him like this and he will not leave him'*. Also, the same interviewee believes that the future lies in the hand of God and nobody knows what is going to happen tomorrow.

Interviewee (13) expressed her acceptance for her child's situation as follows, *'It is fate and the bounty that God gives us; therefore, I am thinking how I can help my child. Even though there is no clear future, I can anticipate a future'*.

This might give an indication as to how belief and faith affects the mothers' perspective towards the child's disability and how this becomes a source of hope

as well as providing the parents with a feeling of security that God will not let them down.

Receiving good services helped the mothers feel relieved and feel that there is hope. This was expressed by interviewee (6).

*She said, 'I felt more comfortable when my child went to this centre. The Service provided a high degree of quality. In turn my relationship with my daughter became better. The support we received helped me to understand her needs better.'*

One can predict from the mothers' statements that positive feelings create a positive attitude towards the child, develop a sense of acceptance and strengthen the relationship between the mothers and their children. Contrarily, a lack of good services is a worry for the mothers. Parents who have received a mixed diagnosis left them weary and with bad feelings. Interviewees 5 and 11 have very strong negative feelings about their children's future in the light of the services that they are receiving now. They believe that if the child it would have been better if the child had died because there is no clear future for him. The feeling of sorrow, anxiety, worry, denial, shock, depression and self-blame were also monitored throughout the mothers' talks.

Interviewee (18) said, *'I do feel sorry for him especially when comparing him to his young brother'*.

Another interviewee said, *'I do get nervous and stressed but I am trying to control myself by praying'*.

One mother expressed her denial as follows, *'I would imagine that there is a child with autism, but not a man with autism'*.

Interviewee (1) reported, *'I am used to the situation, however I do feel stressed'*.

One mother said, *'Sadness is not a solution; therefore, I have to work and help my child'*.

The previous statements on the mothers' emotions might lead one to suspect that the mothers' moods swing between a mixture of both positive and negative feelings which might motivate them to work hard sometimes but hinder them at other times. Interviewee (11)'s statement is a good example of such a situation, being between both a positive effort of trying to help and negative feelings of a minimal outcome.

She said, *'it is an overwhelming feeling of shock and depression after using any intervention approach and the child showing only limited signs of progress'*.

The mother's expectations for the intervention outcomes and the hope of getting a better result from it might lead her to think negatively if the result does not match her expectations. Both understanding and feelings show at this point, a limited understanding of the nature of autism or perhaps the effectiveness of the treatment and high expectations would create such overwhelming feeling.

Indeed, there are other difficulties that the mothers might come across, taking into account that the discussion is limited to the common problems that are frequently cited by the majority of the mothers. These problems might emerge from external factors such as the father's role in the child's situation and the impact of society. For example, the father's limited role in the child's situation was the notion held widely by the mothers. For example, Interviewee (6) reported that the father is supportive and tries to do his best to help but sometimes he puts pressure on the mother by looking for perfection. According to her, the husband expected her to provide all of her time and effort. He expects her to stop thinking about anything apart from the child, such as taking a vacation or registering for college. The father thinks that the mother should do everything herself.

Interviewee (15) said, *'if the father stays with his child on one day for two hours, he will refuse to do it the next day. I am telling you, it is all down to the mother'*.

This might lead one to think that the fathers are limited in their involvement, especially on the child's physical care rather than on a financial or moral one. Consequently, more pressure would be on the mothers in terms of care and education. The mother, on a daily basis, has to face society and its lack of awareness about autism as a disability. The pressure resulting from the lack of

awareness about autism might begin on a small scale and only within close family members or friends and then extends to include members of the community, whether in markets, hospitals, or any public places. One mother gave a detailed explanation of the suffering society places upon the mothers as it relates to the child's difficulty.

She said, *'Most of all, I feel that society doesn't accept her. Some people don't accept her by any means: She is sick. How...? Why is she like this? What is the reason? This is most of the family.'*

And she continued to say,

*'Some understand her situation. They have followed her situation and have noticed the change in her. Others don't understand how she has suddenly become sick. This comes especially from some relatives. They don't understand her situation.'*

Another example that exemplifies the amount of pressure that society might put on the mother is as interviewee (20) stated.

She said, *'people's lack of acceptance, whether those around us or even people on the street, is very stressful. My child looks older than his age; he is three years old but looks like six, so they judge his behaviour based on his appearance as if he is spoiled or lacks discipline.'*

Interviewee (10) expressed her shock of the lack of society's awareness by saying, *'They are insufficient. In our society, people don't realize the meaning of an autistic child. For example, when he was sick I took him to a doctor. When she saw his movement, I told her it was a feature of autism after which she asked what autism meant. She is an educated person, yet she asked this question. What would other people say about this?'*

Thus, the impact of society's lack of awareness about autism on the mother has been mentioned by all interviewees. Accordingly, isolation from and avoiding the community was the most noticed reaction the mothers mentioned.

For instance, interviewee (2) said, *'If there is a gathering of relatives, I can't take him. I leave him at home.'*

While interviewee (1) said, *'I try not to be out for long. My going out becomes so limited, it is just if there is a necessity. After one hour or one hour and a half maximum, I am back at home.'*

#### 5.3.2.2 Difficulties Associated with the Child

In terms of the child's limited abilities, the mothers reported several aspects of such limitations. Language delay, a lack of self-expressing, attention deficit, an understanding deficit and social limitation, with different severity levels, were mentioned by almost all of the mothers. The child's behaviour was also one of the mothers' concerns. The mothers reported the following example of their children's difficult behaviour. These include hyperactivity, violence, repetitive behaviour, routine preferences, lack of independency and bizarre behaviours. The following are some examples of the mothers' understandings, feelings and actions associated with their child's limitations and difficulties.

Almost all of the interviewees reported that their children lack or are limited in their ability to talk and most of them link the ability to speak to the skill of expressing one's needs and emotions.

For example, interviewee (14) said, *'I think his inability to talk is the main problem. If it's improved many problems will be solved'*.

Interviewee (11) thought that her child's lack of ability to talk prevents him from being able to communicate and learn.

She said, *'My main problem is that I want him to be able to talk so I could communicate with him and teach him. I do feel guilty because I do not know how to teach him'*.

Interviewee (12) said, *'It is difficult to know what he wants, his inability to talk and express his needs are tiring'*.

However, the mothers who have talkative children or children who are able to talk reported that their children are limited in terms of expressing themselves. This was the case for interviewees 15 and 17.

One of them said *'he has never called me. He was two years when he could memorize anything you tell him. He could memorize any chant, but of course he would repeat it in a broken way'*.

On another occasion, she mentioned her effort to utilize the child's ability to talk by teaching him how to express, to respond to orders and to ask for things.

She said *'I used to tell my child about everything around him... I taught him. When he started to talk, he could speak and ask when he wanted something because he had vocabulary. Also she added, 'It is by training as he doesn't know. I told his brothers not to stop until he calls their names. I told them to act as if they didn't hear him until he calls a name.'*

It could be anticipated that some of the mothers might have a mixed notion about the individual's capability to talk verbally and the skill of expressing oneself. This is because the capability to talk is an ability, whereas expressing oneself is a skill that could be developed even with the absence of the capability to talk verbally. Therefore, the child's limitation in expressing his/her needs and emotions is also problematic, not only for those who lack the ability to talk but also for those who are able to talk. Thus, this mixed notion between the child's ability to talk and the skill of expressing oneself might also refer to the mothers' limited knowledge about the nature of autism and its resultant problems on child development.

Attention deficit was also mentioned by the majority of the mothers, in which most of them expect that a child's inability to concentrate and pay attention affects their ability to understand.

Interviewee (17) said, *' I think if my daughter concentrates, she will be fine because when I communicate with her she focuses, but she doesn't when she is running or when she is busy doing something.'*

Similarly interviewee (7) said *'he does not understand or concentrate, his communication is poor, he loses his concentration after one minute'*.

Interviewee (5) said *'my child is difficult; he does not understand me, even when I hold him and talk to him he looks at ceiling'*.

The majority of the mothers are still struggling to tackle this difficulty.

For instance, interviewee (7) continued to say, *'I think his ability to concentrate and understand are getting better after sending him to the centre where he is exposed to speech therapy'*.

Interviewee (3) explained her child's difficulty in concentrating by saying, *'No matter how hard you call him, he doesn't answer you. Sometimes you feel that he understands that you are calling him, and he looks at you, but not as a normal child would interact with you and come to you. I try to make him understand that these are your clothes, these are your shoes, this is your hair and these are your eyes. It is still early...I'm still at the beginning of the road....it's still early'*.

Some of the mothers tried to develop a range of home training approaches to improve and maximise their children's ability to concentrate. Some of these approaches are discussed in the difficulties of services in the next section in which home schooling and other methods are discussed as methods that some of the mothers use to train their children.

The child's social ability was also emphasized by the mothers as being problematic and heart breaking to them because they notice how lonely their children are. Interviewee (16) wishes that her child could enjoy his childhood as much as the rest of the children.

She said, *'He does not enjoy playing with children; he prefers to play by himself. Even when other children try to play with him, there is no response. I feel sad when I hear other children comment on him as stupid'*.

Another mother said, *'I wonder if he felt saddened by his inability to interact and integrate with other children, as he shows interest in other children but cannot follow them'*.

Several mothers who have been interviewed were trying to accommodate their child's social limitation by including their children in society and helping them to engage in society.

For example interviewee (10) said, *'When there is a gathering at my parents' or somewhere else where there are other children coming, I intentionally take him with me. Also, sometimes I don't sit with the women. You'll see me with the children encouraging him to look at one child or to throw the ball at another child. I want him to be close to them. I want him to change'*.

On the other hand, some mothers choose to protect their children from the discomfort due to their limited ability to socialise with others. This was exemplified in several of the mothers' reported practices.

For instance, one mother said, *'I would stay home with the child to avoid any difficulties or go to indoor places very early so there are no crowds. In emergencies, and if my child is left home with the nanny, he would be given his favourite activities only when I am not at home.'*

In relation to the child's behaviour, the mothers varied on their compliance over what is the most difficult behaviour. Nine out of the twenty interviewees stressed that hyperactivity is a problematic behaviour.

For example, interviewee (3) stated, *'He is so hyper even with the Risperdal (drug). When he first took it, it calmed him down. Now, he has gone back to being like this. He never sits still. He is not focused when I take him out. It is a real problem because he doesn't walk with me. He always runs'*.

Similarly interviewee (12) described her child being hyperactive and aggressive. She said, *'Physically, he is very strong. Actually, his physical strength is scary. One day, he pushed me and I nearly fell down. In addition, his hyperactivity makes me feel tired.'*

Eight mothers reported another form of aggressiveness, which is self-affliction behaviour that is exhibited by the child in a stressful situation, for example, if something is removed from the child or if s/he wants to express his /her needs.

The child's restricted interest either in food or in activities was also a source of complaint by the mothers.

For instance, one mother stated, *'The problem with my child is that he has no interests to keep him busy within the house. Any usual children's toy doesn't interest or attract him'*.

This illustration is one example that has been provided by the mothers which exemplifies her child's limited interest in activities. Another mother explained her child's limited interest in both food and activities.

She said, *'She doesn't accept just any food. She only eats some kinds of food like potato chips, water, milk or juice. She would never accept eating anything other than this. It is just that; she would never accept any new kind of food. Any new thing in her life, she refuses it. It is only one thing that she keeps doing and nothing else. She watches T.V., only for the songs there'*.

Bizarre behaviours such as eating non-food items, for instance dirt and paint chips, or crying and laughing without clear reason were also behaviours that worried some of the interviewees.

One of them said, *'He always gets diarrhoea because he eats dirt, wood and things on the floor'*.

Another mother said, *'He never eats his food directly. What he does is throw the food on the floor and then take it from there and eat it'*.

Crying and laughing without clear reason was reported by almost half of the interviewees.

Interviewee (4) said, *'All of a sudden, he might run, scream, laugh or he might cry. I would say to myself what makes him do that. This makes me distressed and I wish that I could get inside his mind to know what he has.'*

Indeed, a great number of examples of the children's limited ability and behaviour problems were reported by the mothers as difficulties that the mothers were struggling to confront. However, the aim was to be exclusive and not to include them all, as discussing a few of them would clarify the difficulties that the mothers might confront in relation to the child being within the autistic spectrum.

### 5.3.2.3 Difficulties Associated with Services

As discussed earlier, knowing that the child has autism was not enough for the mothers. Needs would emerge at this point over the meaning of autism, its causes and its treatments. Some examples discussed previously were that the mothers found that information and advice provided by the professionals at the diagnosis stage were sometimes limited, insufficient and often disappointing. As a result, the parents had to face this difficult period with only a minimal amount of information about autism and how they could help their children.

Interviewee (8) described this difficult time as, *'After getting the diagnosis, no one explains to you how to deal with your child, where you should go, what you should do, what is helpful and what is not. It is all down to the parent's efforts to find out about services and information'*.

Interviewee (17) was very explicit, she said, *'There are services available, but nobody tells you where you find them. I got really exhausted searching for centres. I searched the Internet; nobody tells you where to go'*.

She continued to exemplify what a parent needs after getting the diagnosis, *'The most important thing is to define autism for the parents, the reasons, the symptoms and how it is known that the child is autistic. Then, to point out the centres and the methods that will teach them as parents. We need to apply methods at home. I need the means to help me. I want books and educational aids to know how to communicate with my daughter and how to make her communicate in society. I am diligent and I need to get the benefit. I search the Internet, but it is a personal endeavour and is still insufficient'*.

The previous examples illustrated that the difficulties here are not only related to the mother or the child directly, but there are also other external factors that might be related to finding services that accommodate both the children with autism and their parents. The mothers experienced this part of their journey in identifying and trying different solutions, depending mostly on themselves. Their efforts to find a solution varied and were affected by several factors including their understanding, belief and hope. Several actions have been applied by the

mothers with the aim of finding solutions to their children's problems. After examining the mothers' difficulties in relation to having a child recently diagnosed with autism, the final part of the interviews focused on the mothers' expectation over the child's future and how they see their child's future in the light of current services. The aim was to identify the types of support and help that the mothers expect to obtain through the services. These actions were identified through a close reading of the mothers' responses to the interview questions. These could be summarised as follows: educational intervention via special schools or centres, medication, home-training, special diet, spiritual treatment 'ruqia', oxygen treatment and chelation therapy.

As discussed previously almost all the mothers mentioned that educational intervention, including behavioural, speech, play and occupational therapies, was one of the recommended treatments that been suggested by the professionals. Therefore, educational interventions were the most reported implemented approach by almost all of the interviewees, as finding an educational placement was their first main concern. Thus, 11 out of 20 of the mothers reported that they have managed to place their children in private schools and centres. On the other hand, three mothers reported that their children are on the waiting list in order to be able to receive free services. The remainder are still in the process of looking for a school. One can predict that educational intervention was one of the preferred treatment options implemented by the mothers. This is due to the advice provided by the professionals once the child was diagnosed.

One mother said, *'The psychiatrist told me that the most important thing to do is to find him a school'*.

Current intervention services are limited in terms of their intervention approaches that are mainly based on educational intervention. As there is only one newly established centre in the Kingdom, located in Riyadh, that uses new intervention approaches such as oxygen treatment and chelation. Moreover, four mothers, for instance, refer to another Arabic country and their expertise, comparing to the services in Saudi Arabia. One of them said *'I read about doctors and programs being used in Egypt and Jordan. But here? There is nothing'*.

In the process of finding schools, some mothers mentioned that the professionals provided them with list of schools and centres that provide educational services for individuals with developmental delay such as autism. Others also reported that some of the professionals recommended specific centres. For example, interviewees 1, 5, 6, 14, 15 and 18 said that the doctors recommended to them the name of the centre where they can obtain an educational intervention for their children. Three of those mothers were happy placing their children in that centre; however, the other three found the cost to be very expensive.

The mothers were not sure if there are any services directed to them as parents, as all of the services only accommodated children. For example, interviewee (15) answered the question about services being provided to the mothers.

*She said, 'I don't know what to say...there isn't any. There was a director of one of the centres who told me that there would be a Mothers' Celebration Day at which we make a program. I thought it was a program in which parents give information that would be of benefit to us, and that every mother would talk about her experience and about other things that would be of benefit to the mothers of autistic children. What happened was that she brought us an outsider who talked about how to count in maths using the analogical method; to explain to us how to make the child a genius in maths. What has this to do with me?'*

Several examples of the mothers' complaints over the diagnostic services and intervention facilities have been discussed and exemplified above. The mothers' expectations reflect their dissatisfaction over the current services, starting from the diagnostic service then passing through to the intervention services. Several mothers emphasised the lack of the full package of services where a child could be diagnosed and receive interventions at the same place.

For example, interviewee (8) said, *'why we do not have a centre that provides health care and all of the intervention services at the same time, why should we have to go to different places to get the diagnoses and a variety of places to get intervention'*.

Others reported that services exist, but that public ones are very limited, where the child waits a long time till s/he gets the services. However, finding trusted

and convenient schools in terms of specialized educationalists and reasonable fees was not an easy task for the mothers because there is only one public autism school in Jeddah, where the interviews were conducted. According to the mothers, school fees are very expensive and this was reported by almost all the mothers, both those who can afford the fees and those who cannot, where the cost is about £5500 a year.

One mother commented on that by saying, *'I don't think we have enough centres. Even for those that exist, they exploit the parents' wish to see their child improve even a little bit. The money they charge is unbelievable'*.

Other issues that concern the mothers about their children's educational intervention were related to having a qualified teacher. One problem is the student teacher ratio, as a number of the mothers said it is difficult for teacher to handle more than three autistic children in the class.

She added, *'Let's say twenty children in one classroom as it is impossible for the teacher to take care of more than one or two autistic children'*.

Another problem is the teachers themselves. Some schools employ teachers who are Arabic speakers; however, the accent might be different from the child's accent which might cause confusion to the child, which was reported by two mothers.

Regardless of the fact that the mothers' experience with the school's performance is still limited as their children have just started receiving the intervention, the mothers reported a couple of issues related to the school's effectiveness. First, they could not notice any significant improvement in their children.

For instance, interviewee (7) stated, *'I get bored and I want an immediate solution'*.

Within the same context interviewee (11) commented *'I think it is my problem as I am looking for quick results'*.

The mothers' comment on the child's progress after being exposed to educational intervention highlights a very important issue over their understanding of the nature of autism and the fact that educational intervention would take time before the outcome would be noticed.

Another way of obtaining available educational services for individuals with autism was interviewees that used the Internet; 9 out of 20 mentioned that they checked the Internet to obtain information, not only about the nature of autism, its symptoms and treatment, but also to look for services. Home schooling was also reported by some of the mothers as a means of educational intervention applied at home. Several mothers have tried their own natural way to teach their children some skills. For example, interviewee (15) explained her efforts to teach her child a range of skills.

*She explained, 'I have started giving him exercises such as to match, to draw circles and to colour. I taught him the names of the parts of the body, and I made him familiar with the people around him. 'This is your sister Lama, this is Ahmad, this is Radi and you are Othman'. I didn't use pictures for communication... I did it naturally as for the parts of the body, geometric figures, colours, fruit, vegetables, cars and other ways of transportation.'*

One mother started home intervention by hiring a private teacher whereas one mother mentioned that she volunteered at a private autism centre so she could be trained and learn how to deal with her child. Thus, exposing a child to intervention, whether at home or at school, according to the mothers would relieve them of stress because their main aim is to help their children to be independent and educated to develop skills of independency.

*For instance interviewee (3) said, 'It is the father's first objective, and mine too, to teach him how to depend for himself; I don't want him to be a burden on anybody. When I first knew about this, I told his father that we will not live forever. He shouldn't be a burden on anyone.'*

*Interviewee (17) reported, 'I wish I could teach her the best. I want to make use of the years to begin a normal life and study normally. I don't want her to be more delayed.'*

Educational intervention was not the only solution the mothers were trying. Along with an educational intervention, the mothers mentioned they are implementing or trying other therapeutic approaches that might bring relief their children. Several mothers reported that they used prescribed medication based on

a physician's advice as stated earlier. Five mothers reported that they believe in diet and its effect on the child's ability to concentrate. Therefore, they start to implement a healthy diet on their children.

As reported by one of the mothers, *'My sister and I started reading. I started to prevent sugary food little by little, then preservatives as in potato chips and sweets. These things were rare at home, and we started having healthy food.'*

Alternative medicine such as herbs, vitamins and minerals was also reported by some mothers as a treatment option. Two mothers said that they are applying such treatments on their child and another three are thinking of doing so. Also, within the same context of using medication one mother has reported that she applied both the oxygen treatment and chelation (removing heavy minerals from blood) on her child at the same time. In addition, eight mothers reported that they applied spiritual treatment by visiting 'sheikhs', a religious person who reads specific Qur'anic verse and supplication with the aim of healing illnesses. Almost all of the mothers reported that they have tried more than one way of treatment in their journey in identifying a solution for their loved one. Indeed, close reading of the mothers' speeches through the interviews took place with the aim of finding the reasons behind how and why the mothers choose specific methods of treatment or decide to try more than one treatment.

Another issue highlighted within the same context of educational intervention, is the child's role in society. Many of the mothers wish that their children were included within society.

One of the mothers said, *'I wonder why they don't mix autistic children with normal ones at normal schools at least once a week to see their communication with them. Why don't they make field trips for each group of autistic children to see the world together as they understand one another? I haven't seen a group of autistic children together. It was only my daughter, so if I see a group of them together I may get ideas from them... I don't know.'*

Awareness programmes that were supposed to be directed towards society to educate people about disability in general and autism in particular are rare according to the mothers. One mother expressed her view.

She said, *‘Nobody knows what autism is. There is not even a piece of news about autism on T.V. Also, in the magazines or newspapers there is nothing. It is only the Internet and that's it.*

The following is an example of a mother's suggestion over the media's role in raising people's awareness.

*‘On T.V. channels, they should assign about ten minutes a day to talk about some kind of disease like they did when there was swine flu’.*

Eleven interviewees are looking for a drug treatment where autism could be treated completely.

For example, interviewee (12) said *‘I wish there was a medication or that they discover a medication for autism so my child would be rid of autism and be a normal child’.*

At the conclusion of the survey, the mothers were asked to give their suggestions as if they were in a position to develop a training programme for a parent similar to their case. What do they think the programme components should consist of? Thus, replies to these questions helped in spotting some needs that were not covered through the interview questions or confirming what the mothers want. The generated findings showed that most mothers think that illuminating the meaning of autism and its causes to the mothers is the first thing such a programme should focus on. The second priority was providing the mothers with the skills that would help them in training their children at home.

For example, interviewee (11) *‘to get education is the best thing for me and my child, as this would help me in teaching my child using my own accent and implementing my system, at this point everything in my child life would be used to train him, for example, eating time, playing time and sleeping time will be a training time.*

Some mothers put great emphasis on the importance of showing empathy and cooperation between the professionals and parents. According to some of them,

the professionals might be the gateway of hope that relieves the parents' frustration, or they might be a source of disappointment.

For example, interviewee (14) expressed in her talk the expected role of the professionals as follows, *'When you get frustrated, the 'professionals' give you the hope that enables me to start over and continue my journey. They might direct you to ways or at least help you to accept the situation'*.

On the contrary, another mother said, *'I went to a psychiatrist once. Instead of guiding you what to do, he was saying that it is a blessing from God and that God will reward us because of him and make it up to him. I agree with what he said, but it was as if he was telling you to surrender and accept it and do nothing about it, that your son will never change as there is no cure for autism'*.

Both views exemplify the role that the professional plays in accommodating the parents and easing their frustration.

#### 5.3.2.4 Needs and Actions

Some of the mothers' feelings that were associated with the child's limitations and difficult behaviour have been discussed earlier. However, all of the mothers agree on the idea that the child's limited ability and difficult behaviours are stressful and painful for them. The way the mothers confront such limitations and difficult behaviours were varied. Thus, a few examples of the mothers' way of confronting their children's difficulties were highlighted previously. Further patterns of parenting practices that have been reported by the mothers are discussed. After getting the diagnosis, the child becomes the mothers' first priority. The mothers' efforts on helping their children according to them were mainly dependent on the individual's endeavour to help the child.

For example, the mothers were asked to respond to the question 'describes your child's day'.

One mother said, *'Before the diagnosis, I didn't really spend much time with her, but now I spend most of my time for her. I try to be organized and to wake up early to finish the house chores before she wakes up. Then, I start being with her'*.

The previous statement exemplifies the importance of time management for the mother in such a case where a lot of effort needs to be taken to help the child. Another mother comments on the amount of effort taken for the children in such a case as follows:

*‘They are exhausting and annoying. It is a big difference from the normal child who knows about everything. When you tell a normal child about something, he understands as he knows. There are a lot of things missing’.*

Thus, the minority of the mothers reported that they are trying to manage and organize their time. On the contrary, a number of the mothers find it difficult to manage their time and make a balance between the extra effort that the children with autism need and other life and family demands.

Interviewee (12) expressed that by saying *‘I am trying to find extra time that could be devoted to him; but there are other children and other concerns that need to be tackled’.*

Another mother said, *‘I want to know how to organize time for her. How should I make use of the time to benefit her?’*

Related to the idea that a child with autism needs extra effort to raise them, according to the mothers it is not only extra effort but also the special way of handling them. Similarly some mothers reported that they are working on themselves to improve their skills while others think it is difficult to do so without help.

However, even those who were trying to work on their parenting skills think that getting support would ease the process of identifying and acquiring such skills. Here is an example of some of the efforts from one mother.

*‘I try to develop my skills to help her in everything and exploit everything for her benefit. When you understand her way and sing for her she follows you because, she loves songs. If she laughs at something in it, I make use of that to repeat the same situation and add things to it.’*

Several examples were provided to explain ways of accommodating the child by observing the child strengths and weaknesses and building on that.

Interviewee (15) said, *'The minute the mother sees the child doing this routine movement such as flapping, she has to hold him and keep him busy with something else. I used to see my son stand with toes pointed, so I immediately held him and made him busy with just anything to make him forget it.'*

This is another example of a mother's effort to improve her skill so she could accommodate the child's undesirable behaviour. Within the same context of examining the mother's practices to deal with the child difficulties, one mother commented and some examples were provided,

*'I also feel that there are many mothers like me who have suffered what I have suffered and drifted from one place to another. I am telling you I still need experience, but I don't know how to get it'.*

On the other hand some mothers reported that they feel that they have their hands tied and think that they need support so they could help the child at home. For example Interviewees 12 and 13 share the same opinion in relation to their lack of skills to deal with the child. As both of them said in almost similar words, *'I want to know how to deal with him'*. As a result, one can conclude from both mothers that those who are trying and those who are struggling think that they need support and help to direct them and utilize their effort to help their children. Providing the child with everything s/he wants without asking or being overprotective were further practices that were identified through the interviews. Such practices might prevent the mothers from being effective in training their children at home regardless of the fact that they are very eager to do so. An example of that is as interviewee (11) reported.

She said, *'My problem is I know everyone's needs at home so I have provided them with their needs before they ask, especially my child with autism. I feel kindness and empathy towards him because of his case'.*

Providing a child with all his/her needs was repeatedly reported by the majority, 14 out of 20, of the interviewees. A few mothers mentioned that they are trying to motivate and utilise the child's ability to ask, to choose or to express needs.

For example, interviewee (5) said, *'I do give my daughter the opportunity to choose her clothes or food to enhance self-confidence'.*

Thus, one can anticipate providing a child with everything might lead also to dependency which was one of the mother's concerns. According to them, the child depends on the mother or any adult in charge to meet his/her needs, such as self-care in feeding and getting dressed.

Interviewee (8) said, *'My daughter is dependent even if the cup of water is in front of her and she is thirsty, she would stay put till I give it to her'*.

In terms of being overprotective several examples were generated from the mothers' conversations.

For example, Interviewee (3) commented on her child's lack of sense of danger stating, *'I never let him go off, I don't know whether or not he senses it.'*

One can deduce from the previous response that the mother is being overprotective which limits the child from being exposed to normal daily experiences and learn from them. This mother was not the only one being over protective. Examples of the mothers being overprotective were mentioned by the majority.

Some mothers also reported that they might use force to stop unwanted behaviour that the child might exhibit, such as refusing to eat or self-harming behaviour.

For example, interviewee (5) said, *'I would force him to eat with his father's help. He would hold him and I would feed him myself.'*

A lack of consistency in dealing with the child when teaching a skill or managing undesirable behaviour was also identified, that the mothers apply as a form of their way in raising their children. Several examples were reported by the mother.

For instance, one mother said, *'He is still bottle feeding. I tried to stop him but he got sick as he refused to eat anything, so we got worried and returned it to him'*.

A similar example of the mother being inconsistent is toilet training as the mother might use a diaper sometimes and stop it at other times. All these examples show there is a great need for time management and parental strategies to make the training more effective.

The following paragraph summarises first, the questionnaires findings and then, second, the main interviews findings based on previous analysis of both the questionnaires and the mothers' interviews. As both methods aimed to closely

examine the mothers' experiences of having a child with autism and identifying difficulties that might be encountered as a result to that. Both the questionnaire and the interview findings were subject to analysis according to a constrictive grounded theory approach where a constant comparison between both sets of findings took place in order to identify the mothers' on-going needs by interviewing the mothers of newly diagnosed children with autism and by inquiring about those who have older children with autism via the questionnaires. The comparison results fed into identifying and designing a parental training programme which in turn led to implementing and evaluating the training programme. Thus the whole process of consistence comparison of the data findings helped in answering the current research inquiries in identifying a relevant framework that facilitated in establishing parental training services within the Saudi context.

### **5.3.3 Summary of Interviews Findings**

Based on the previous discussion, autism could be considered as a main difficulty and central category in the earlier analysis which crystallizes and links the other three core categories which have been identified from the interviewees; difficulties, needs and actions. The following are the common findings that emerged under each category and its sub categories which exemplify the mothers' experiences of having a child with autism:

❖ Autism as a difficulty would create difficulties related to:

➤ **Child:**

- Language delay
- Lack of self-expressing.
- Attention deficit.
- Understanding deficit.
- Social limited ability.
- Hyperactivity.
- Violence.
- Repetitive behaviour.
- Routine preferences.
- Lack of independency.

- Bizarre behaviours.

➤ **Mothers:**

- Suspicion that the child might have a problem.
- Hard feelings associated with the diagnosis.
- Limited information on autism and interventions.
- Limited understanding of the nature of autism.
- High expectation of intervention outcomes.
- Sense of responsibility associated with confusion on addressing the problem.
- Mixed of positive and negative feelings towards the child.
- Strengths and weaknesses in parental practises.

➤ **Services:**

- Get the diagnosis:
  - ✓ Procedures of referrals.
  - ✓ Professionals' practice dissatisfaction.
  - ✓ Lack of interdisciplinary team.
- Limited public services.
- Expensive private services.
- Poor service quality.

❖ Autism as a difficulty would create a need for:

➤ Information.

- Problem clarification.
- Diagnosis verification.
- Recommendation.
- Information on:
  - ✓ Autism.
  - ✓ Interventions services.
  - ✓ Intervention approaches.

➤ Skills:

- Time management.

- Observations.
  - Planning intervention.
  - Utilize parental practises.
- Support:
- Emotional support.
  - Solutions.
  - Self- empowerment.
- ❖ Autism as a difficulty would call for actions:
- Pre-diagnosis.
- More observation.
  - Consult professionals.
  - Search Internet.
  - Looking for services.
  - Get the diagnosis.
- Post-diagnosis.
- Look for information about autism.
  - Look for information about services.
  - Find services.
  - Decide on intervention approach.
  - Try different intervention approaches at the same time.

The following tables summarises the link between the difficulties, the emergent needs and actions associated with them at the pre and post diagnosis stages as previously analysed. Thus, the first table exemplifies the pre-diagnosis stage difficulties, needs and actions. Autism was a hidden and unknown difficulty for the mothers at that period. The mothers suspected that the child might have a problem. However, the suspicion was based on the mothers' observations of whether the child had health issues or his/her developmental delay. The second table summarises the post-diagnosis period difficulties, needs and actions when autism as a difficulty becomes apparent and the mothers were more able to recognize its manifestation in their children.

Table 15 Difficulties Needs and Actions Pre Diagnosis

	Difficulties	Needs	Actions
Mother	Suspicion child might have a problem	Clarification	<ul style="list-style-type: none"> <li>• More observation</li> <li>• Consult professionals</li> <li>• Search Internet</li> <li>• Consult professionals &amp; Internet</li> </ul>
Services	Get the diagnosis: <ul style="list-style-type: none"> <li>• Procedures of referrals</li> <li>• Professionals' practice dissatisfaction</li> <li>• Lack of interdisciplinary team</li> </ul>	<ul style="list-style-type: none"> <li>• Verification</li> <li>• Recommendation</li> </ul>	<ul style="list-style-type: none"> <li>• Consult physicians</li> <li>• Consult one or more professional</li> </ul>
Mother	Difficult feelings associated with diagnosis	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Solutions</li> </ul>	<ul style="list-style-type: none"> <li>• Looking for services</li> </ul>

Table 16 Difficulties, Needs, and Actions Post Diagnosis

	Difficulties	Needs	Actions
Mother	Limited information on: <ul style="list-style-type: none"> <li>• Autism</li> <li>• Interventions</li> </ul>	Information on : <ul style="list-style-type: none"> <li>• Autism</li> <li>• Interventions services</li> </ul>	<ul style="list-style-type: none"> <li>• Look for information on autism.</li> <li>• Look for information on services.</li> </ul>
Services	<ul style="list-style-type: none"> <li>• Limited public services</li> <li>• Expensive privet services</li> <li>• Poor services quality.</li> </ul>	Information on current provided services	<ul style="list-style-type: none"> <li>• Find services.</li> <li>• Decide on intervention approach.</li> </ul>
Mother	<ul style="list-style-type: none"> <li>• Limited understanding of autism nature.</li> <li>• High expectation of intervention outcomes</li> <li>• Sense of responsibility associated with confusion on addressing problem</li> <li>• Mixed of positive &amp; negative feelings</li> <li>• Strengths &amp; weaknesses on parental practises</li> </ul>	Information on : <ul style="list-style-type: none"> <li>• Autism nature.</li> <li>• Intervention approaches.</li> </ul> Skills on : <ul style="list-style-type: none"> <li>• Time management</li> <li>• Observations</li> <li>• Self empowerment</li> <li>• Planning intervention</li> <li>• Utilize parental practises.</li> </ul>	<ul style="list-style-type: none"> <li>• Read &amp; research about autism.</li> <li>• Try different intervention approaches at the same time.</li> </ul>

#### 5.4 Comparisons between the data collected in different methods

Both questionnaires and interviews within the current study were designed to examine the parental experience and identify their needs as a result of having a

child with autism. Thus, each method targeted a different sample. Detailed descriptions of both the methods and their aims have been discussed earlier within the context of the current study design. The reader is referred to the methodology chapter for further information. However, a brief review of the questionnaire and interview targets and design are given at this point. The questionnaires targeted a general and relatively large sample of parents of children with autism with no inclusion conditions. On the other hand, the interviews were targeting only novice mothers who have children that are newly diagnosed with autism with inclusion conditions. Both the interview and questionnaire findings have helped in drawing a clearer picture of the parental experience of parenting a child with autism. The interviews' findings have helped in examining the pre-diagnostic stage closely and the mothers' immediate needs directly after receiving the diagnosis. On the other hand, the questionnaires have highlighted the mothers' on-going needs after living with autism for a long-term period. Indeed, this justifies the role of applying both methods to obtain data from multiple resources, as both samples could be seen to vary in terms of their long-term experience of having a child with autism. Obtaining multiple parental views and combining them would help in suggesting a practical parental training programme that meets the parents' needs based on their perspective.

Indeed, the previous illustration provided an in depth descriptive analysis of both methods where a constant comparison within each of the methods' findings were applied. The aim was to identify similarities and differences between the mothers in relation to their experience of parenting a child with autism. Once each method has been analysed and its findings generated separately, a parallel comparison technique between both sets of findings were applied because a constructive grounded theory approach is the current study framework. Therefore, a constant comparison of similarities and differences between the interview and the questionnaire findings has been applied in order to achieve the same goal of discovering the mothers' common and on-going needs. The following section illuminates first, the identified common and on-going needs; second, an interpretive analysis of the interview and questionnaire findings' 'comparative

process'; third, provides justification of the programme components based on the findings and the analysis.

#### **5.4.1 The Common and On-Going Needs within the Questionnaires and Interviews**

The common and on-going needs based on both groups' responses examined the mother's experience in relation to their children being within the autism spectrum. These needs were identified and based on the comparative analysis process. The importance of such a comparison has helped in recognizing the immediate and on-going needs of the mothers, and that feeds into determining the programme's components and designing the parental training programme. Therefore, the main aim of the study to develop a parental training programme was met. The following table summarises the identified results based on the comparison process of both the interview and questionnaire findings. Indeed, aiming for a consistent analysis, the questionnaire findings were grouped in the light of the three categories, difficulties, needs and actions, which have been drawn based on the interviews' analysis.

Table 17 Common and On-Going Needs of the Interviews and Questionnaires

	Interview findings	Questionnaire findings
<b>Difficulties</b>		
<b>Mother</b>	<ul style="list-style-type: none"> <li>• Sense of responsibility associated with the confusion on addressing the problem.</li> <li>• Mixed of positive &amp; negative feelings.</li> <li>• Strengths &amp; weaknesses in parental practises.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents have a sense of their role.</li> <li>• Parents sense the child’s difficulty but that might be mixed with a sense of hope.</li> <li>• Child with autism plays and interacts with siblings and the siblings take responsibility of the child.</li> </ul>
<b>Services</b>	<ul style="list-style-type: none"> <li>• Limited public services.</li> <li>• Poor services quality.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants are aware of the current limited services and are dissatisfied.</li> <li>• Offering parental training services is important.</li> </ul>
<b>Needs</b>		
<b>Skills</b>	<ul style="list-style-type: none"> <li>• Time management.</li> <li>• Planning intervention.</li> <li>• Utilize parental practises.</li> </ul>	<ul style="list-style-type: none"> <li>• The quality of time and the diversity of activities practiced were conflicting.</li> <li>• Parents are concerned to improve their child’s language, communication and social skills.</li> </ul>
<b>Information</b>	<ul style="list-style-type: none"> <li>• Limited information about the nature of autism and the available services of the professionals.</li> <li>• Internet is the number one source to obtain knowledge about autism and services.</li> </ul>	<ul style="list-style-type: none"> <li>• Limited information about the nature of autism and the available services of the professionals</li> <li>• Internet is number one source to obtain knowledge about autism and services.</li> </ul>
<b>Support</b>	<ul style="list-style-type: none"> <li>• Emotional support.</li> <li>• Self-empowerment.</li> </ul>	<ul style="list-style-type: none"> <li>• Child with autism has a stressful impact on family members; mother, father and siblings respectively.</li> <li>• Parents were not confident in their ability to educate their children.</li> </ul>

The previous table highlighted the common difficulties and needs that were identified as common between the questionnaire and interview findings. In terms of parental actions, these were anticipated from the activities that the parents reported that they exercise with the child and the source of information that they consult in order to obtain knowledge about autism. This is because within the interviews the mothers were either asked directly or they have mentioned spontaneously in their conversation about actions that they have applied to confront difficulties and the source of information that they have consulted. The following table illustrates both the mothers’ comments on the type of common activities and the sources of information used from both the interviews and the questionnaires.

Table 18 Common and On-Going Needs of Questionnaires

Activities	Source of information
<ul style="list-style-type: none"> <li>• Self-care: Eating, Dressing and Toileting.</li> <li>• Physical: Walking and Racing.</li> <li>• Entertainment: T.V, Computer Games, Drawing, Colouring and Singing.</li> <li>• Social: Integrating with other children and tickling and cuddling.</li> </ul>	<ul style="list-style-type: none"> <li>• Mostly the Internet then a professional.</li> <li>• Limited books and media role.</li> </ul>

The above findings mostly reflect the post-diagnosis stage difficulties and needs, as both the interviews and the questionnaires deeply examined this stage. Although the questionnaire examined some aspects of the pre-diagnosis period, this stage was studied more deeply within the interviews. Examination of this stage is critical because the development of a parental training programme targeting novice mothers who have a child newly diagnosed with autism immediately after getting the diagnosis is the study's main aim. Therefore, identifying the mothers' on-going needs for this period would feed into the developmental process.

#### 5.4.2 The Interpretive Analysis of the Questionnaires and Interviews

The process of comparing the findings from the interviews and questionnaires could be seen through three interrelated levels. The first was identifying the common and on-going needs of the mothers from both sets of findings. Second, interpreting these findings and discussing them within the context of the current study's aim. The third level was grounding the parental training components and design based on the generated findings. Therefore, after highlighting the common needs from both the interviews and the questionnaires in the previous tables, the attention is now directed towards interpreting them closely, so that the experience of parenting a child with autism for both novice and expert mothers would be compared and investigated. The comparison process would cover the following: the questionnaire and interview samples, the demographical characteristics, the diagnostic process, and sources of pressure and the resultant needs and accompanying actions.

#### 5.4.2.1 Demographical Characteristics

Studying the characteristics of the family is essential to the current investigation as it is pivotal to the main aim of the research, developing a parental training programme. Therefore, being aware of the learners' characteristics would help in designing such a parental training programme. Indeed, some theoretical considerations of adult learners have been discussed, and are highlighted in Chapter four, with a further explanation on applying this theoretical consideration being provided within the following description of the training programme (Chapter six). The following table summarizes the demographics' similarities of both the interview and the questionnaire sample.

Table 19 Demographics

	Interviews	Questionnaires
Total Participants	20	251
Participants	100% Mothers	79% Mothers
Child's Age Range	2 to 6 years old	34% 3-5 years old
Child's Gender	75% Male 25% Female	81% Male 19% Female
Family Size	45% Small 35% Medium 20% Large	96% Medium 52% Small 66% Large
Autism Recurrence	1 Case (5%)	17 Case (7%)
Mother's Level of Education	44% Graduated 36% High School 11% Middle School 9% Elementary	54% Graduated 27% High School 12% Middle School 7% Elementary
Father's Level of Education	50% Graduated 35% High School 15% Middle School	62% Graduated 26% High School 12% Middle School
Socio-economical Level	75% Employees	99% Employees

Reading through the previous information on both the samples' characteristics, one can anticipate that both samples share almost similar demographical features. The interview sample, which in this case could be regarded as a small sample,

reflected the larger questionnaire sample in terms of the parents' demographics. This might, to a certain extent, indicate the reliability of the study sample, considering that even the questionnaire sample is not necessarily a representative sample of families of children with autism in Saudi Arabia. However, these noticeably demographical similarities help in anticipating the future parental training programme and how it would accommodate parents with almost similar characteristics. Accordingly, the present study took into account the previous results when designing the training program. For example, the parental training was designed to accommodate mothers with a variety of educational levels. This has led to applying a variety of materials and teaching approaches in order to accommodate the educational level diversity. A further discussion of the training programme components and design is given in the next chapter.

#### 5.4.2.2 Diagnostic process

Both the interview and the questionnaire findings shows that there is no significant time difference between the first time a specialist was consulted and the child getting diagnosed. Within the questionnaire sample the majority of children were diagnosed between 2 and 5 years old, and similarly, for children within the interview sample their age ranged between 2 and 6 years old. This indicates that diagnostic services are developing in Saudi Arabia. In contrast, those who are receiving an early intervention programme within the 2-6 years age group were minimal compared to those who have received the diagnosis. For example, 34% of the questionnaire sample in the age range 3 to 5 is receiving intervention services whilst only 7% received early intervention services when they were less than four years old. Moreover, the majority, 45% of the children within the questionnaire sample who are receiving intervention services, were between 6 and 11 years old. Similar to this, for 11 out of the 20 children within the interview sample the mother reported that they had found an educational intervention for their children. This might suggest that there are shortages in intervention services in Saudi Arabia where most children do not get exposed to an intervention once they diagnosed. Indeed, the current study could be seen as a step towards filling the gap within the intervention services' shortages. Therefore, providing parents with knowledge and skills once the child gets diagnosed would

help the parents to accommodate their children's difficulties and make the best use of the early child development for their first five years.

#### 5.4.2.3 Sources of Pressure and Their Resultant Needs and Accompanying Actions

Referring to the illustrated summary of similarities from both the interviews and the questionnaires, the samples' difficulties, needs and associated actions in Tables (17) and (18), as well as the idea that having a child with autism is a difficulty that creates a series of difficulties and needs for the parents, the following findings were generated.

A parental sense of responsibility was shown in both of the findings. However, parental confusion in addressing a child's problem, the parental positive and negative feelings towards the child, the parental strengths and weakness in their practices and the parental confidence in their ability to intervene and educate the child might hinder the sense of responsibility. In other words, one can conclude that limited information on the nature of autism and the current services provided for parents at the post-diagnosis stage is the first difficulty that the parents might encounter as a result of having a child with autism. Indeed, the absence of such information would lead to a parental confusion in confronting the child's problem. Having such services would accommodate the parents' fear and stress by providing them with the support that they need, such as, information about the nature of autism and intervention approaches. According to the current study interviewees, parenting a child with autism is different from parenting a normally developing child as this needs extra effort and special skills. Consequently, parental strategies are limited, as is information on the nature of autism which means limited skills needed to encounter problems resulting from autism for a child. This in turn might lead to the emergence of both negative and/or positive feelings which might be associated with strengths and weakness on parental practices or vice versa. Thus, this might lead to explaining the reason behind the parents' limited trust in their abilities to intervene and educate their children.

Accordingly, the previous parental dilemma of parenting a child with autism would call for:

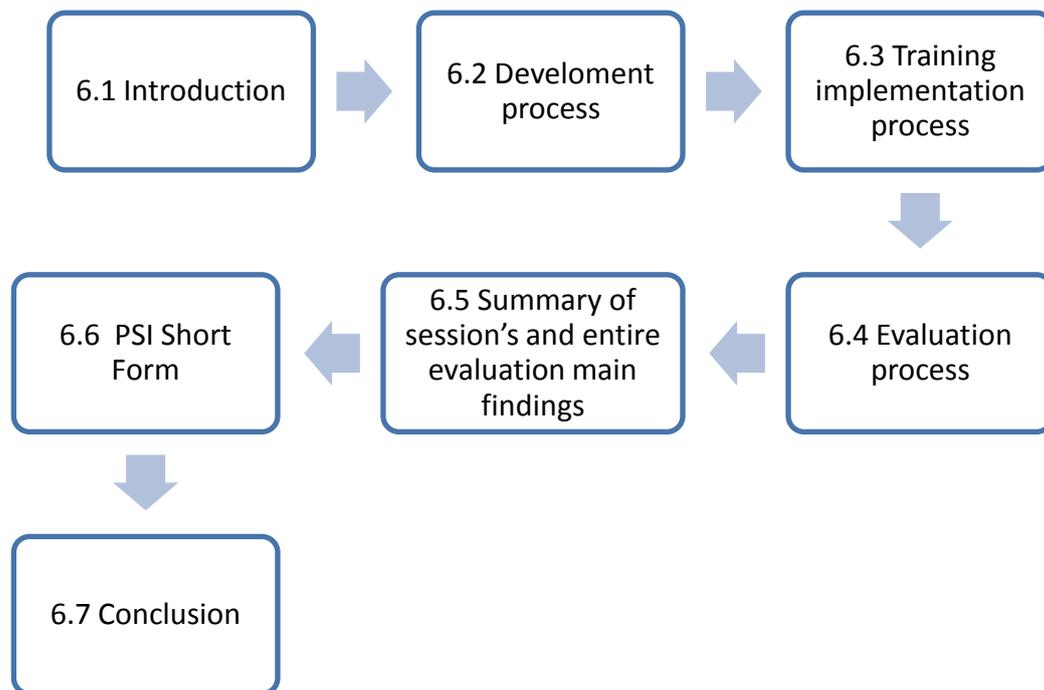
- Information on the nature of autism, available services and autism current intervention approaches to accommodate the parent's limited knowledge associated with autism.
- Skills on time management and planning interventions to utilize parental practices.
- Emotional support by enhancing positive thinking, networking with other mothers to improve the mothers' self-empowerment.

## **5.5 Conclusions**

To sum up, the previous illustrations that examined the parental experiences of parenting a child with autism have identified the common and on-going needs of the mothers. Identification of those needs feed into determining the training programme components and design. The previously identified needs could be summarised under three major areas; these include, the need for information, the skills and the empowerment. Each area consists of secondary needs attached directly to them and fulfilling these are essential in order to fulfil the main ones. Thus, utilizing the outcomes of designing, implementing and then evaluating the training programme are discussed in further detail in the following chapter (6). The aim of this chapter was to identify the parental needs based on examining their experience that was exemplified in their responses to the interviews and the questionnaires inquirers.

# Chapter 6: Parental Training Programme Design and Implementation

Figure 19 Structure of Chapter Six



## 6.1 Introduction

As consistently mentioned throughout the previous chapters, ‘developing a parental training programme that would lead to an early intervention home-based programme to accommodate novice mothers of children with autism’ is the main research aim. Several data collection methods were applied to fulfil the current study’s aim. Analysing collected data that aimed to examine parental experience in relation to having a child with autism identified the common and on-going needs for such parents. These needs were grouped under three main categories, being the information, the skills and the empowerment. Each category covered additional needs that relate to the main need directly. Indeed, identifying parents’ needs could be seen as the raw materials that nourish the parental training components. However, having such raw materials in hand was not enough, as the

procedure of designing, delivering and evaluating such training is a challenge. It requires sensitivity in making the best use of the raw materials and tailoring them to meet the training's main target in providing the mothers with practical and easy to access techniques. Therefore, the purpose of this chapter is: first, to describe the designing, implementation and evaluation process of the training programme; second to discuss the outcomes and implications of implementing such a programme.

## **6.2 The developing process**

In devising the current parental course, several factors have been considered. These include the mothers' needs and characteristics, the researcher's role as the programme designer and facilitator, the cultural context and adult learning theories. Chapter four has highlighted and discussed these considerations extensively within the research design context. Therefore, the following illustration exemplifies the researcher's understanding and concerns in devising the training course based on the above mentioned considerations. The overall planning steps that have been undertaken will be highlighted first. This is followed by a detailed description of the curriculum content. After that each of the programme sessions will be fully discussed.

### **6.2.1 The overall planning steps**

Several steps have been undertaken to design the parental training programme; a detailed description of each step's role will be provided. This is followed by a diagram to exemplify the overlapping relationship between these steps.

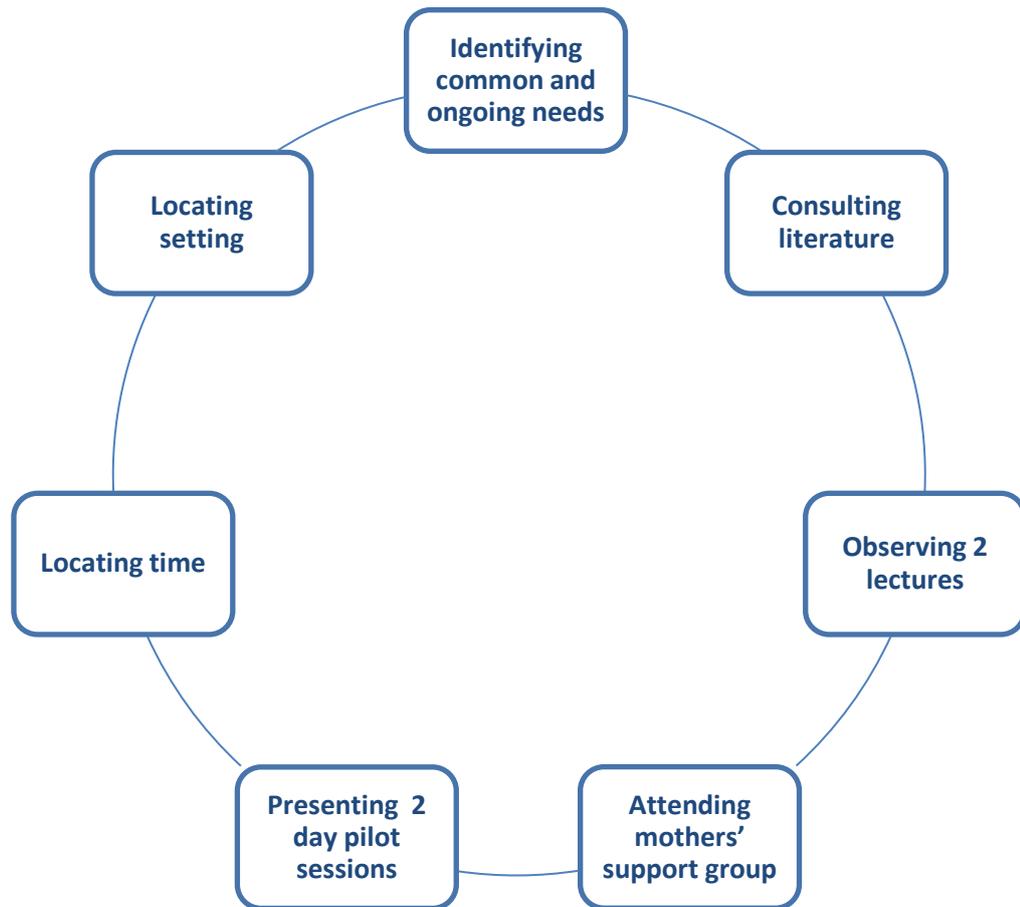
1. Identifying common and on-going mothers' needs based on a constant comparison of both the questionnaire and the interview findings.
2. Consulting the current literature on autism to develop the curriculum content based on the identified needs.
3. Observing two lectures, one entitled 'Stress Management' and the other 'Home Intervention Based on Portage' that target the mothers who have children with autism, at one of autism centre in Jeddah. The aim was to observe the presenters' approaches in providing such a course and the mothers' motivation, concerns and engagement in

the discussions, considering such a ‘one day lecture’ ran as part of the centres’ efforts to educate the mothers about autism. They were delivered by teachers within the centre or invited speakers from colleges or universities who are specialized in this field of education. As a result of this, in designing the current programme, specific attention was directed to make sure that the provided information is accessible and the presentation accommodated the diversity in the mothers’ educational level. In other words, a friendly atmosphere was created and the pure academic way of delivering was avoided, as these factors should be considered. Therefore, to balance and to confront the challenge of simplifying the latest knowledge available on autism and incorporating the knowledge, the modern academic teaching style, which designs and uses a ‘course for all’ theory in adult learning was implemented, as one can anticipate that the mothers aim by attending such a course is to gain strategies enabling them to improve their parenting style to fit their children’s needs. In addition, such a course is expected to ease the difficulties for the mothers by providing them with easy to access information.

4. By attending the mothers’ support group’s monthly meeting, the objective was to get close to their “real life” and capture their needs in a natural setting. This support group was established by a mother of a 12 year old daughter with autism. The group aim is to support the mothers of children with autism and raise society’s awareness of such a category of people. The mothers gathered monthly to share their experiences and concerns regarding parenting a child with autism. Indeed, this natural observation of the mothers chatting with each other reduced the researcher’s subjectiveness, as the role of the researcher was more observational than participative, which helps to minimize the extent of the researcher’s influence over the mothers’ expressions throughout the interviews. Indeed, the topics of discussion were discussed in almost every meeting which revolved around the current provided services and available intervention approaches. This reflects the mothers’ main concern in finding solutions to confronting their children’s difficulties. Moreover, observing the mothers at those monthly meetings revealed that they hold expectations over the professionals’ role. These observations led to the re-evaluation of the researcher’s practices within that context and based on the expectations and insights provided by the respondents; the researcher adjusted some professional practices in order to improve the researcher’s performance based on the mothers’ recommendations.

5. Presenting a two-day pilot session to different groups of mothers in order to test the information accessibility, with the approach being to provide information, having the ability to capture the attention and engaging the mothers, and to answer questions. Therefore, specific efforts were made in writing and organising the content of the parental training curriculum by integrating modern teaching aids, such as PowerPoint and videos to present the course curriculum, as this curriculum is targeting participants with learning specificity. Moreover, providing the pilot sessions inspires the idea of introducing a pre-training agreement. This agreement clearly states the realistic expectations of the programme for each of the participants.
6. Determining the training type length, time, days and dates. The training was designed to be run as group-based to cover five main sessions divided into six weeks. Several reasons justify the rationale behind group-based training. First, to allow the mothers to share their experiences of parenting a child with autism, as this would fulfil one of the parental training objectives in providing the mothers with empowerment and emotional support. Second, accommodating as many as possible of the novice mothers of newly diagnosed children with autism once they have received the diagnosis, as this also one of the study's aims in bridging the gap of the shortage of early intervention services provided for children with autism in Saudi Arabia.
7. The training was conducted for two hours a day, two days a week. This was based on the participants' views and the amount of the information to be presented.
8. Dividing the trainees into morning and evening groups to fit with the mothers' time. Six mothers participated in each group.
9. Set up the physical setting and catering for the food and drinks.

Figure 20 Planning steps



## 6.2.2 Curriculum content

The following discussion describes how each identified aspect needs information, skills and the empowerment to shape and feed into the development of the programme components.

### 6.2.2.1 Information

As previously stated, based on both the interview and questionnaire findings the need for information was one of the mothers' common and ongoing needs, considering that the novice mothers with newly diagnosed children with autism are the current programme targeting group. Therefore, generic knowledge about the nature of autism was provided which included the following topics:

1. Providing the mothers with detailed information about:
  - ✓ Autism definition, characteristics, sub-type and conditions that may coincide with it.
  - ✓ Autism diagnostic criteria, process, and importance.

- ✓ Autism causes.
  - ✓ Intervention approaches.
2. Discussing the autism nature within the context of the developmental stage.
    - ✓ Developmental types, stages and characteristics.
    - ✓ Autism characteristics in relation to child development.
    - ✓ Sensory processing systems and its role in enhancing a functional development of the brain.
    - ✓ Positive emotional affect in enhancing brain development.
  3. Discussing environmental experiences and their role in stimulating the child's growth.
  4. Discussing the requirements of establishing home-based training programs.
  5. Discussing conditions and quality in considering which services to choose when providing the intervention for the child.

#### 6.2.2.2 Skills

It was also definite from both the interviews and the questionnaire findings that the mothers need to acquire some skills to be able to parent a child with autism and confront the resultant difficulties of autism. Following, are examples of the skills that been covered within the training program.

1. Developing analytical thinking skills in the light of thinking steps and how this could be used in understanding both the mother's and the child's behaviours. This skill would help the mothers to understand how the mothers' behaviours affect the child and vice versa.
2. Enhancing the skill of observation so that the mother would be able to identify the child's strengths and weaknesses. This skill would help the mother to develop sub-skills that include:
  - ✓ The skills of identifying targeted objectives for home-based educational intervention.
  - ✓ The skills of prioritizing intervention objectives.
3. Discussing the skills of developing and evaluating a home-based intervention programme.

- ✓ Presenting some examples of some educational intervention approaches that could be implemented in the home setting, such as play therapy, social stories, floor time, and task analysis to name a few.
  - ✓ General educational advice that could be considered when applying the discussed intervention approaches such as teaching consistency, rewarding policy, and allowing enough time for improvement.
4. Enhancing the skills of flexibility and creativity in the use of more than one way to achieve the training objectives.
  5. Discussing ways to improve time management skills.

#### 6.2.2.3 Emotional support and empowerment

Parenting a child with autism proved to be a difficult and stressful job for the mothers. This was found in both the interviews and the questionnaire findings. Also, the Parental Stress Index/ Short Form (PSI/SF), when applied on the mothers' pre and post attending the parental training, the results have shown that the mothers have a high level of stress. The following are some examples of emotional empowerment that have been covered within the current parental training programme.

1. Stimulating a positive emotional attitude towards the child's difficulties and its related problem in the light of the Qur'an and the Sunnah directives.
  - ✓ The difficulty and suffering are a natural part of human life.
  - ✓ The believer is afflicted.
  - ✓ The disability type of shortage and shortage is part of human nature.
  - ✓ Believe in destiny.
  - ✓ The confidence in obtaining relief.
  - ✓ Follow the people of patience.
  - ✓ The certainty in good reward both in life and hereafter.
2. Discussing the importance of the family role in the child's life and development. This includes the family relationship profile, family cooperation and keeping and sustaining the spouse relationship.

3. Discussing the child's rights (financially and socially) and how to obtain them.
4. Highlighting the family's right to claiming services, such as educational, psychological guidance and counselling.
5. Discussing the family's rights when discussing the child's individual educational plan with educationalists.

The previously illustrated skills, knowledge and family empowerment techniques were covered throughout the training sections, as these aspects were provided according to the programme's fluency, which is discussed within the implementation section. The following discussion highlights each session's components.

### **6.2.3 Programme sessions**

The current training was devised to be run in five sessions divided over six weeks, two hours a day and two days a week. Each session offers a mix of the information, the skills and the emotional empowerment that have been highlighted in the previous section. Within this section, a detailed description of each session's objectives, components and outcomes will be provided. Thus, the following table will summarize the parental training curriculum that has been covered in the programme's sessions.

Table 20 Programme Sessions and Components

Session	Topic & Components	Reference for Components
<b>One</b>	Supporting Family Is Priority:  (1) Brief introduction to the study's objectives in the light of interviews questionnaires findings. (2) Pre-Training agreement discussion. (3) Analytical thinking skill. (4) Inspire positive emotions and Attitudes. (5) Family and child's rights.	Alkeedar, (2006). Qur'an and Haddith (profit tradition)
<b>Two</b>	How Can We Understand Autism?  (1) Autism definition. (2) Diagnostic criteria. (3) Diagnosis process. (4) Importance of diagnosis. (5) Autism sub types. (6) Disorders might coincide with autism. (7) Autism theories. (8) Facts and Figures about autism. (9) Types of interventions. (10) Intervention service (how to choose, its conditions, factors of success)	Delfos, (2005) Durig, (2005)
<b>Three</b>	Autism Characteristics and Child Growth Stimulation: (1) Autism characteristics. (2) Relationship between the growth of brain function, physical growth, and social emotional growth. (3) Aspects of growth. (4) Growth verse learning (5) Learning and learning tools. (6) Sensory integration and autism. (7) Mental functional capacity (growth and functions of the brain) linked to autism. (8) Social emotional development function and features linked to Autism Characteristics. (9) Nature versus nurture. (10) How to support the child's growth? (11) Effects of Emotional experience on brain growth function. (12) Experiences that the child must be exposed to which are supposed to help and stimulate growth. (13) How daily life experiences could be invested to stimulate the child growth? (14) Requirements to develop home-based training program.	Greenspan, (2006). Greenspan, (2004)
<b>Fourth</b>	Home-Based Intervention Necessity and Skill: (1) Tips to manage the child and the mother's time. (2) Prioritize the child's training objectives. (3) Develop home-based intervention plan. (4) Choosing the methods of implementation (i.e. behaviour modification, play approach, social story approach). (5) Strategies to address difficult situations flexibly.	Gray, (2007) Levine & Chedd, (2007) Martine & Pear, (2006)
<b>Fifth</b>	Changing Negatives into Positives: Guest speaker who is a mother of a child with autism and educationalist within the field of autism was invited and presented this session to the trainee mothers to share experience of being a mother and special education teacher for autistic children with the mothers	

### 6.2.3.1 First Session: Supporting the family is a priority

Providing family support is the main target of the current programme. Therefore, the first session discusses the importance of providing family support as a priority. This session highlights the pre-training agreements of the programme, objectives of the programme session, the programme components and the outcome of the first session of the training programme.

✓ Pre-training agreement:

These agreements clearly state the realistic expectations of the programme for each of the participants. These are:

1. Training does not provide magical solutions.
2. Training helps in understanding problems, identifying and acknowledging its dimensions.
3. Training helps the mothers to discover both her own and her child's capabilities.
4. Training attempts to cover aspects that have been studied and determined from interviews and questionnaires findings.
5. Training helps to develop the home-based intervention plan and sets goals.
6. The main goal of the training is to provide the parents with help and support immediately after their child's diagnosis. This would help in shortening the time and efforts parent might spend in overcoming the shock. Therefore, the possibility of drawing a plan on solid ground would eliminate fragmented efforts and conflicting decisions.

✓ Session objectives:

The first session plans to achieve the following:

1. Create an atmosphere of intimacy between the trainer and the mothers.
2. Create an atmosphere of intimacy between the participating mothers.
3. Discuss the training program components with the mothers to ensure full satisfaction of trainees and modify the curriculum if necessary.
4. Clarify the reasons of providing the training course in six weeks instead of an intensive two week course. These reasons are to:

- a. Give the trainees time to understand and digest the information provided and to offer them a chance to consult the trainer in case of misunderstanding or confusion.
  - b. Give the trainees a chance to implement and to examine the learnt skills and to consult the trainer when needed.
  - c. Give the participants a chance during the training period to develop a small supportive group amongst themselves.
  - d. Ease the pressure on the mothers and take into account their other obligations.
5. Create opportunities to discuss aloud the problems facing other mothers.
  6. Create opportunities for the mothers to vent their stress and negative experiences.
  7. Raise the mothers' awareness of both their rights and their children's rights.

✓ Session Components:

The first session consists of the following:

- i. Brief introduction to the study's objectives in the light of the interviews, questionnaires, and findings.
- ii. Pre-Training agreement discussion.
- iii. Analytical thinking skills.
- iv. Inspire positive emotions and attitudes.
- v. Family's and child's rights.
- vi. Sessions' evaluation.

✓ First Session Outcomes:

By the end of the first session, trainees were expected to be able to:

1. Establish acceptance, trust and relationships between the mothers and the trainer and between the mothers themselves.
2. Apply analytical thinking skills and understand its role in facing problems.
3. Acquire positive emotions and attitudes towards the child's difficulties in the light of the Qur'an and Sunnah.

4. Develop an awareness of the feelings that the mothers might hold towards both themselves and their children's disability and understand the role of the feelings in guiding the mothers' behaviours.
5. Develop an awareness of both the mother's rights and the child's rights.

#### 6.2.3.2 Second session: How Can We Understand Autism?

The first session focused on the much needed parental support. The support came in the form of emotional support and understanding. The second session focused on the intellectual support and the knowledge of the autism condition.

##### ✓ Session Objectives:

The main concern of the second session was to provide the mothers with essential information about autism. This information includes the following:

- a. Autism spectrum disorders nature, definition and causes.
- b. Autism diagnoses criteria, procedures and importance.
- c. Intervention approaches.
- d. Conditions that should be considered when:
  - ✓ Looking for an intervention service.
  - ✓ Applying the intervention approach.

##### ✓ Session Components:

The second session components were:

- a. Autism definition.
- b. Autism diagnostic criteria.
- c. How to diagnosis autism.
- d. Importance of the diagnosis.
- e. Autism sub-types.
- f. Disorders that may coincide with autism.
- e. Autism in the light current autism theories.
- g. Facts and Figures about autism.
- h. Types of interventions.
- i. Intervention services (how to choose, its conditions, factors of success)

✓ Session Outcomes:

Based on the presented information that would be discussed during the meetings, a trainee would be able to gain a clear understanding about autism concept, its causes and the appropriate intervention methods to use.

### 6.2.3.3 Third session: Autism Characteristics and Child Growth Stimulation

The third session is a continuation to what has been established within the second session in terms of providing the mothers with essential information which is supposed to enhance their understanding of the autism nature. Therefore, autism characteristics and its resultant problems on the child's normal development would be covered at this point along with the skills that the mothers would need to acquire in order to be able to address the child's difficulties that are associated with autism's characteristics.

✓ Session Objectives:

The third session aimed to provide the mothers with both information and skills at the same time. It discussed autism characteristics in the light of the child's normal growth and this would be followed with a presentation of methods that could be applied to stimulate the child's growth. Therefore, the two main objectives are:

- First: Providing the mothers with information on:
  1. Sensory integration and autism.
  2. Brain growth and its function linked to autistic traits.
  3. Positive emotional experience affects in teaching skills and stimulating brain growth and functions.

Second: Developing the following skills:

- a. The ability to observe and identify the child's level of functional development
- b. The ability to observe the child's strengths and weaknesses.
- c. The ability to identify home-based training objectives based on previous observations.
- d. The ability to prioritise home-based training objectives.

✓ Third Session Components:

These components are derived from the previous objectives and consisted of:

- a. Autism characteristics.
- b. Relationship between the growth of brain function, physical growth, and social emotional growth.
- c. Growth and aspects of growth.
- d. Growth versus learning.
- e. Learning and learning tools.
- f. Sensory integration and autism.
- g. Mental functional capacity (growth and functions of the brain) linked to autism.
- h. Social emotional development function and features linked to autism's characteristics.
- i. Nature versus nurture.
- j. How to support the child's growth.
- k. Effects of emotional experiences on the brain's growth function.
- l. Experiences that a child must be exposed to which are supposed to help and stimulate growth.
- m. How daily life experiences could be invested to stimulate the child's growth.
- n. Requirements to develop a home-based training program.
  - Observe and understand the child's sensory responses to environmental stimuli.
  - Determine the child's level of functional development.
  - Prioritise training skills at the child's level of functional development.
  - Consider autism's characteristics.

✓ Third Session Outcomes:

By the end of the session the mother would be expected to:

- A. Obtain and understand the following information:
  1. The aspect of brain functional growth, physical growth and emotional social growth linked to autism's characteristics.
  2. The role of positive emotional experience in the brain's growth function.

B. Implement the following :

1. Observe and determine the child's sensory response to environmental stimuli.
2. Observe and determine the child's level of functional development, which reflects the key stages of brain function growth.
3. Identify home-based training objectives.
4. Prioritise home-based training objectives.

6.2.3.4 Fourth session: Home-Based Intervention Necessity and Skill:

The fourth session of the programme focussed on the importance of establishing home-based intervention and the skills that need to be developed to apply such an intervention. This session also addressed the mothers' need for both information and skills to confront their children's problems that has resulted from having autism.

✓ Session Objectives:

The fourth session aimed to:

First: Provide the mother with basic information that includes examples of types of educational intervention.

- i. Applied Behavioural Analysis.
- ii. Play as an educational input.
- iii. Social story.

Second: Develop the following skills:

- a. Enhancing time-management skills for both the mother and the child.
- b. Prioritising the child's training objectives.
- c. Developing and evaluating a home-based intervention plan.
- d. Enhancing flexibility and innovation skills in the use of more than one way to achieve the training objectives.
- e. Developing the skill of patience and giving the child enough time to master the targeted goal.

✓ Session Components:

- a. Tips to manage the child's and the mother's time.

- b. Prioritise the child's training objectives.
- c. Develop a home-based intervention plan.
- d. Choosing the methods of implementation (i.e. behaviour modification, play approach, social story approach).
- e. Strategies to address difficult situations flexibly.
- f. Being up-to-date with what is new within the autism field.

✓ Session outcomes:

By the end of the session, the mothers should be able to:

A. Comprehend the following information:

- i. Develop a general understanding of Applied Behavioural Analysis principles and implementation strategies.
- ii. Understand and utilize play as an educational intervention.
- iii. Develop a general understanding of the social story approach, principles and implementation strategies.

B. Be able to implement the following :

- i. Time management skills for both the mother and the child.
- ii. Prioritise intervention objectives.
- iii. Develop and evaluate a home-based intervention plan.
- iv. To become more flexible and innovative in the use of more than one method in order to achieve intervention objectives.
- v. Allow a child enough time to master targeted skills.

#### 6.2.3.5 Fifth session: Changing Negatives into Positives:

A guest speaker, who is the mother of a child with autism and an educationalist within the field of autism, was invited and presented this session to the trainee mothers.

✓ Session Objectives:

The session planned to fulfil the following aims:

- A. To share the experience of being the mother of a child with autism and a special education teacher for autistic children with the mothers.

- B. To emphasise that being an educationalist does not mean there are no obstacles to face.
- C. To discuss both the family's roles and the child's rights.

✓ Session components:

1. Who is the speaker? (speaker introduces herself).
2. The diagnosis journey and the stages of acceptance (denial, anger, fear, acceptance).
3. Reaction as a mother and teacher.
4. Acceptance and working with the child.
5. Actions (understanding the child, supporting the child, empowering the researcher).
6. Exercises to build strength and positive thinking.
7. Our religion is our life. The speaker shared her adaptation processes that she developed in order to accommodate and help her child based on the Islamic values.
8. Achieved hopes in relation to the child / hopes yet to be fulfilled.

✓ Session outcomes:

By the end of the session the mother should be able to understand the following ideas and attitudes:

- a. That the specialist mother also has difficulties.
- b. That family's role in enhancing the child's development is more important than the specialist's role.
- c. That an everyday situation is an effective way to train the child if it is invested flexibly and creatively.
- d. That the mother should look after herself in order to be able to support her child.

### **6.3 Training Implementation Process**

As discussed previously one of the study's main aims is to endorse the mothers and enhance their ability to help the children on a home-based early intervention that is easy to implement via training especially designed to serve this purpose.

Indeed, the data analysis revealed on identifying the mothers' needs on three different dimensions. These included: emotional support, information and skills. Therefore, when designing and providing such training, taking into account that the trainees are the mothers of newly diagnosed children with autism. It also considers that they are special cases who have specific needs which should be addressed at this stage. The following gives a brief illustration of the current training implementation procedures. This would cover the programme's sequence, the justification of the sequence and the delivery approach.

### **6.3.1 The programme's sequence:**

1. Designing the teaching sessions:
  - ✓ Four parental training sessions designed by the researcher.
  - ✓ One session designed by the guest speaker without interference from the researcher's side.
2. Prioritising the training components in a coherent order as follows:
  - ✓ Trainees and trainer getting to know each other.
  - ✓ Illuminating the training aims and its process of development to trainees so they could anticipate the general training outcomes.
  - ✓ Introducing a thinking process in facing a new situation (starting from analysing and understanding the situation, through making sense of the situation and ending with the associated behaviour) as an introduction to addressing the importance of understanding the situation, feeling associated with the understanding and its effects on one's behaviour. Accordingly, the mothers would acquire the skills of understanding their behaviours and the feelings associated with the behaviours in the light of the thinking process.
  - ✓ Discussing coping strategies in the light of the Qur'an and Sunnah. This is considered to be quite original and reflects an essential part of the training programme as it takes into consideration the Saudi contexts.
  - ✓ Highlighting the family role in:
    - ◆ Enhancing the child's development by comparing to the specialist's roles.
    - ◆ Obtaining the child's rights.
    - ◆ Maintaining the family and marriage relationship.

- ✓ Providing general information about the autism's nature, available intervention and the child's developmental stages in relation to autism.
  - ✓ Enhancing the mother's ability to observe and understand their child's growth, strengths and limitations.
  - ✓ Encouraging the mothers to identify her child's needs and assign intervention goals to enhance those needs.
  - ✓ Helping the mothers to prioritise intervention goals and develop an intervention plan.
  - ✓ Discussing various educational approaches so the mothers could choose the appropriate techniques in achieving the intervention plan.
  - ✓ Emphasizing that flexibility, tolerance and optimism are important skills that the mothers should improve as part of their intervention programme.
3. Providing the mothers with presentations, hand-outs and relevant printed materials.
  4. Exposing the mothers to videos as examples to:
    - ✓ Clarify presented information and ideas.
    - ✓ Enhance their observation skills.
  5. Designing exercises to practice observation, prioritising, and developing home-based intervention plan skills (see Appendix H).
  6. The mothers' input and concerns were welcomed and addressed.
  7. Providing the mothers with a list of references of information and videos that were used through the sessions (see Appendix I)
  8. Providing the mothers with a booklet consisting of basic and general information about the autism nature, intervention approaches and existing services (see Appendix J)
  9. Keeping the information simple and easy to access so the mothers obtain an understanding more than obtaining qualifications which falls within the aim as the implementation focuses on simplicity.
  10. Applying group discussions and a self-reflection approach throughout the sessions served as vehicles to facilitate the programme objectives and to utilize group diversity.

### **6.3.2 The justification of the sequence**

The following orientation was provided to be more explicit and justify why the training followed this particular order in covering its components. As mentioned earlier, before exposing the mothers to the targeted training objectives, explaining to the participants the developmental process of the training programme and its components was fairly important because the current programme trainees were the research sample and the identified results were generated from them. Therefore, clarifying to the participants how the programme components are designed (based on the information obtained from the questionnaires and interviews) emphasises the importance of their participation in developing the current programme. Moreover, discussing the curriculum components with the participants helped to accomplish several important targets; these include:

- First, providing the mothers with a general overview of what they would expect to get out of the training sessions.
- Second, making sure the participants are satisfied with the training curriculum components and allowing room for their input so that modifications can take place based on their suggestions. One such modification was based on one of mothers' suggestion that a detailed session on applied behavioural analysis, principles, and implications should be provided.
- Third, laying the foundation for establishing closeness and familiarities between the participants and the presenter before exposing the mothers to the training curriculum.
- Finally, presenting an opportunity for the researcher, the current programme designer and facilitator, to examine the readings and to utilize the acquired information that has been obtained via examining the parental experience.

Indeed, discussing the training programme with the participants could be seen as an orientation or pre-initial step that led to the beginning of the training implementation and as illustrated earlier helped to ease the presentation of the

training programme curriculum. Thus, acknowledging the mothers' feelings helped them to identify, express, analyse their own behaviours and feelings towards their children and themselves. This step was a pivotal first target of the current training programme in which empowerment and self-management skills were integrated into the curriculum by examining their 'inner selves', the mothers are empowered to deal more effectively with a child's difficulty resulting from autism. In order to achieve this target and allow the mothers to examine their behaviour in the light of their understanding and feelings to any new situation they confronted, contemplation in confronting new situations was discussed. The philosophy behind examining the thinking route was to exemplify to the mothers that an individual's behaviour is a product of understanding and feelings associated with any new situation that needs to be tackled regardless of whether that situation is difficult or not.

Accordingly, the mothers were encouraged to adapt and apply the previous strategies to analyse their behaviours which relate to their children's difficulties. For instance, examining the feeling of rejection and dissatisfaction compared to those associated with the feeling of acceptance and satisfaction. The mothers were encouraged to reflect on how an inner feeling of acceptance for their children's difficulties and their role in addressing such difficulties can have a positive impact on their parenting practice. Several examples of the mothers' behaviours were analysed in a group discussion to allow the mothers to share their experiences and examine their behaviours and understand their feelings as this fulfils one of the parental training objectives in providing the mothers with empowerment and emotional support that impact on the parenting practice effectiveness in the long term.

As a continuation of providing emotional support, the importance of discussing coping strategies in the light of the Qur'an and the Sunnah was necessary in order to empower their attitude toward their children because within the Saudi context, the Islamic stance that emerges from strong faith on God's will has a huge impact on people's attitude and behaviours especially when it comes to difficult situations, such as having a child with disability. Therefore, several Qur'anic verses and Prophetic traditions were presented to justify autism as a difficulty

based on the Islamic perspective. The mothers also were encouraged to express and share their attitudes and coping methods in the light of some Islamic values that been adapted and presented within the training curriculum. Indeed, discussing autism as a difficulty within the context of Islamic values and perspective could be considered as one originality within the current parental training because the mothers' faith was utilized as a source of strength to encourage their positive feelings towards the child difficulty. Following the same aim of empowering the mothers, the parental role in helping and supporting the child was discussed and highlighted after presenting both the process of analytical thinking and Islamic perspective within the first section of the training programme. Indeed, the previous sequence of presenting the first session components helped the trainer in;

- Developing a close, empathetic bond and trust with the trainees.
- Empowering the mothers by enhancing their observation skills over their behaviours.
- Empowering the mothers by providing them with positive ideas emerging from Islamic perspectives.
- Empowering the mothers by highlighting the importance of their role in their child's life.

In fact, the first session within the program was covered in four meetings (two weeks). The researcher had to develop a strong foundation of trust between the trainer and the participants and positive feelings before exposing the mothers to: solid and somewhat complicated information and knowledge about autism, and skills needed to meet the child's difficulties.

### **6.3.3 The delivery approach**

After the first session, all of the subsequent sessions were teaching sessions of the core information about autism, its nature, characteristics and educational approaches. All presentations were augmented with videos:

- To clarify presented ideas such as the child developmental stages, growth vs. learning.
- To provide some examples of interventionist and other parents applying discussed intervention strategies with the children with autism.

- To apply exercises designed to develop the mothers' capacity to observe the children and determine strengths and weakness in terms of development.

For example, in the second session, the mothers were exposed to information about autism nature and its resultant problem on the child development and were encouraged to relate the presented information to their children's situation in a group discussion aiming to enhance their understanding of autism. Subsequently, in the third session, the mothers were given exercises to complete individually by having the mothers observing videos segments of children communicating with others and then completing a checklist designed to determine the child's level of functional development. After that, group discussions were encouraged to reflect on the mothers' observations. In further steps, the mothers also were asked to use the same exercise at home to observe their children's level of functional development. Consequently, the mothers' observations on their children at home for two weeks were used to determine the child's strengths and weaknesses in terms of his/her development. In the fourth session, the same observations were used to identify and prioritise home-based intervention targets. Then, the mothers were encouraged to choose the appropriate intervention approach that fits the targeted objectives based on the presented and discussed interventions within that session (social story, behavioural approach, play approach). Several skills such as the mother's child time management, flexibility in applying more than one intervention approach to achieve the targeted skills, and patience in the acquisition of skills were presented and discussed in the light of the mothers' experiences.

The exercises were designed: to enhance the mothers' ability to observe, to facilitate presented information and skills immediately, and to relate the presented information and skills to their real needs in acquiring knowledge and skills that would enable them to understand their children's needs. Examples of exercises on identifying and prioritizing intervention objectives that lead to developing home-based intervention programmes and activities that have been applied throughout the training programme to facilitate its objectives in the light of both the mothers' needs and adapted adult learning approaches, that are

available in Appendix H. Indeed, based on the previous illustration, it is worth reminding the reader that the delivery of the programme drew heavily on the adult learning theories that have been discussed in detail in Chapter four, the research design. The following is the summary of the applied philosophy:

- ✓ The learning principles where learners' needs, rights, prior experiences and motivation were addressed through curriculum components and delivery approach (Knowles et al., 2005).
- ✓ The experiential learning philosophy where participants are encouraged to talk, listen, observe, test and reflect as they engage with the programme content through observation-exercises, informal group discussions and problem solving activities (Kolb,1984).

Despite the fact that the implementations of the training programme was not directly related to learning and teaching, the training was developed to impact the quality and effectiveness of a parenting style that participants could provide in the long term. This is because the programme aims entirely to meet the mothers' strong desire to find a means of support to tackle their children's problems. Therefore, in order to address the mothers' similar concerns and needs that had been identified earlier, along with the participants' demographical diversity, the current programme adapted group discussions and critical reflections as training delivery vehicles. Both approaches would emphasise on the positive aspects of participants' diversity and utilize it throughout the training sessions. Moreover, self-reflection and group discussions would serve as a springboard for the mothers sharing their 'positive' and 'negative' parenting experiences.

## **6.4 Evaluation process**

The programme has undergone constant evaluation; the reader is referred to Chapter four which highlights the reason behind using such evaluations and provides the evaluation forms devising process. Indeed, the current evaluations aimed to assess and critique the programme components and programme delivery process in meeting participants' needs rather than evaluating the improvement on participants' parental practice. This is done for several reasons; first, the generated result of the evaluations would lead to answering one of the research questions on how could programme effectiveness be evaluated? Second, due to time limitations for the current investigation, the focus of attention was directed

towards identifying training components and a training delivery approach that was based on parental needs within the Saudi context whereas, measuring the improvement on parental practice could be seen as a further step that should take place after examining the mothers' satisfaction regarding the training course components and its delivery. Thus, several sources have guided this process:

- Anonymous evaluation forms completed at the end of each session.
- Anonymous overall evaluation form completed at the end of the programme.
- PSI/SF pre- post- attending the training programme.

Therefore, the following are evidence of previous evaluation tools obtained from eight mothers' responses that attended and managed to complete the parental training course.

#### 6.4.1 Session evaluation forms

At the end of each session, the mothers were asked to complete an evaluation form to examine their satisfaction regarding each session. The same evaluation form was applied in all sessions see Appendix (E) The main focus of this evaluation was to assess each session's objectives and delivery so that improvements could be applied to the following programme sessions and the overall training development later on. The form asked the mothers firstly to respond to 14 statements using a 5-point Likert scale (strongly agree, agree, do not know, disagree, strongly disagree), and secondly to answer six open questions to examine the mothers' satisfaction regarding the session. Table 23 shows the number of received evaluation forms from each session. Noting that all the mothers' responses to the fourteen statements within the evaluation form were confined to strongly agree, agree and do not know options. Accordingly, the results from all five training sessions are reported and analysed below.

Table 21 Number of Received Evaluation Forms

Sessions	Number of form
I. Supporting family is priority.	11
II. How can we understand autism?	12
III. Autism characteristics and the child growth stimulation.	9
IV. Home-based intervention necessity and skills.	6
V. Changing negative into positive.	5

## Likert Scale

Within the evaluation form, participants were asked to respond to several questions in which each question was to be ranked in relation to the main question according to five Likert-type rating scale that ranged from (strongly agree to strongly disagree). The questions were also examining the mothers' satisfaction over programme components and its delivery approach. The following tables and discussion illustrate each main question and the overall responses by the mothers to the main question.

Table 22 Session 1-5 Evaluation Results

\*SA= strongly agree, A = agree, DK= don't know, D= disagree, and SD= strongly disagree

Statement of Evaluation	1 <sup>st</sup> session	2 <sup>nd</sup> session	3 <sup>rd</sup> session	4 <sup>th</sup> session	5 <sup>th</sup> session
<i>Total respondents</i>	11	12	9	6	5
<i>the meeting was generally useful</i>	10 SA 1 A	11 SA 1 A	9 SA	6 SA	4 SA 1 A
<i>goals of the meeting were clear</i>	9 SA 2 A	8 SA 4 A	8 SA 1 A	6 SA	4 SA 1 A
<i>meetings' goals have been organized and discuss in an easy and logical way</i>	9 SA 2 A	9 SA 3A	7 SA 2 A	5 SA 1 A	4 SA 1 A
<i>the meeting's objectives have been achieved</i>	6 SA 5 A	9 SA 3 A	6 SA 3 A	4 SA 2 A	3 SA 2 A
<i>the information that was presented and discussed was important to them</i>	9 SA 2 A	9 SA 3 A	8 SA 1 A	5 SA 1 A	4 SA 1 A
<i>The applied exercises helped them to acquire the information and the skills related to the training objectives.</i>	8 SA 3 A	8 SA 4 A	7 SA 2 A	5 SA 1 A	4 SA 1 A
<i>the information was important</i>	9 SA 2 A	9 SA 3 A	8 SA 1 A	5 SA 1 A	4 SA 1 A
<i>the exercises were useful</i>	8 SA 3 A	10 SA 2 A	7 SA 2 A	4 SA 2 A	4 SA 1 A
<i>the way the information presented is appropriate to the content</i>	9 SA 2 A	10 SA 2 SA	7 SA 2 A	4 SA 2 A	5 SA
<i>Were satisfied with the coach's performance (statement #)</i>	11 SA	10 SA 2 SA	9 SA	6 SA	4 SA 1 A
<i>the coach was confident in discussing scientific material,</i>	8 SA 3 A	10 SA 2 SA	7 SA 2 A	4 SA 2 A	4 SA 1 A
<i>the coach responded to the audience's questions in an effective manner</i>	10 SA 1 A	11 SA 1 A	9 SA	6 SA	5 SA
<i>printed material was useful and organized</i>	9 SA 2 A	9 SA 3 A	7 SA 2 A	4 SA 2 A	5 SA
<i>if they intend to apply what they learned in everyday situations</i>	7 SA 4 A	6 SA 4 A 2 DK	6 SA 3 A	4 SA 2 A	4 SA 1 A
<i>they are confident that the skills learned in training could be applied at home</i>	3 SA 6 A 2 DK	3 SA 6 A 3 DK	2 SA 7 A	4 SA 2 A	4 SA 1 A

#### 6.4.1.1 First Session

Reminding the reader that providing the mothers with empowerment and emotional support was the main focus of the first session. As almost all the mothers' responses were between strongly agree and agree options. Moreover, strongly agree was more likely to be the mothers' choice compared to the agree option. Adding to that the open question responses within the second part of the form were consistent with the mothers' responses to the first part. For instance, the first part of the form examined the mothers' satisfaction regarding the usefulness, organisation and presentation of the provided information and skills. However, the mothers reported their satisfaction again within the second part as discussed earlier. Moreover, none of the mothers reported dislikes or encountered difficulties through the session whereas most of the mothers expressed their desire to obtain information and skills within the next sessions. This might suggest that the mothers were open and honest in expressing their feelings regarding the first session components and delivery approach. Reading through the mothers' responses to the second part of the evaluation sheet, where the mothers had a chance to express their opinion over, what they learned from the session? (Question 2). Dislikes or difficulties encountered during the session? (Question 3 & 5). As well as information they wish to obtain or suggestions for improvement? (Question 4 & 6). The following are the mothers' responses according to its frequency in term of what they learned:

- ✓ The importance of the mother in particular and the family role in general in supporting a child with autism.
- ✓ The importance of accepting the child regardless to his/her difficulty.
- ✓ The importance of flexibility and optimism in facing life difficulties.

Only two mothers mentioned flexibility and optimism as the thing they learned from the first session. However, the majority reported more than one lesson obtained from the same session. For example, six mothers emphasized on the importance of their role in supporting the child. Four of them reported acceptance and flexibility along with the importance of their role in the answers. Moreover, five mothers mentioned acceptance along with being flexible and positive in facing the child's difficulty. For example, one mother wrote that 'I have learned from the meeting how to be positive and flexible in facing my problems because

being positive makes me come to life with determination, patience, and hard work to develop my daughter's abilities, as well as believing that whatever professionals provide to her, their role will be limited if I am not there to help and support'.

In terms of difficulties and dislikes, none of the mothers reported any difficulties or dislikes that related to the first session and two of them justified that by saying 'no difficulties as the sessions were useful and organized'. Within the same context, one mother commented that 'I did not face difficulties, however, I felt that my day would be full with many responsibilities and was wondering how I would be able to find time to do what I have to do to be an effective mother'. Indeed, based on that thought, one can anticipate that even though the session was aiming to empower the mothers by enhancing their flexibility, optimism and highlighting the importance of their role, this might put a greater load on some of them. This is due to several reasons (to name a few): size of the family, whether there is any other child with a difficulty in the family, condition of the spousal relationship, and whether the mother is working...etc.

Providing more courses like this was three mothers suggestion. Another mother suggested that to assign one day in which the mothers and children would attend together. The majority of the mothers stated their desire to obtain more information within the next sessions on:

- Ways to understand the child needs.
- Information on intervention method examples (TEACH, Behaviour management, oxygen therapy).
- Ways to improve the child's ability to communicate play and express him/herself.
- Time-management skills.

Indeed, from the mothers' responses it could be anticipated that the first session met its targeted objectives in terms of empowering the mothers' positive attitude and making sure that the provided information was useful and the trainer was able to reach the mothers, capture their understanding and trust.

#### 6.4.1.2 Session two

This session was almost informative in its nature where the aim was in providing the mothers with details of information regarding autism definition, nature, characteristics, subtypes and intervention approaches. In examining participants' satisfaction over this session components and delivery approach, the mothers responses to the evaluation form revealed on the following:

- Eleven out of twelve strongly agreed that the meeting was generally useful and only one mother agreed to the statement (Statement 1).
- Eight out of twelve responses showed the mothers' strong agreement that the goals of the meeting were clear, whereas, 4 participants agreed to the statement. (Statement 4).

The mothers had similar responses to the statement, the meeting's goals have been organized and discuss in an easy and logical way (Statement 3), and the statement, the meeting's objectives have been achieved, 9 out of 12 strongly agreed while 3 agreed (Statement 4).

Similarly, the majority of the mothers, 9 out of 12, strongly agreed that the information that was presented and discussed was important to them. Eight out of twelve strongly agreed that the applied exercises helped them to acquire information and skills related to training objectives. Three mothers agreed on the importance of the information and two agreed on the usefulness of the exercises. In response to the five statements that examined the session delivery approach, 10 received responses strongly agree on their satisfaction regarding the coach's performance and the way the information presented is appropriate to the content and the coach was confident in discussing scientific material while two agreed on previous statements. Only one mother agreed that the coach responded to the audience's questions in an effective manner while 11 out of 12 strongly agreed. Three mothers agreed that printed material was useful and organized and the majority strongly agreed.

When the mothers were asked if they intend to apply what they learned in everyday situations 4 out of 12 were agreed and 6 strongly agreed. However, two

mothers don't know if they are confident that the skills learned in training could be applied at home, 6 mothers agreed and 3 strongly agreed.

Moving to the mothers' responses to the second part of the evaluation sheet, the following findings were obtained in terms of, what they learned from the session?, Dislikes or difficulties encountered during the session?, and information they wish to obtain or suggestions for improvement?

The following were reported by the mothers in terms of information they learned from the second session. It is organised based on the most frequently reported:

- ✓ Defining autism.
- ✓ Knowing autism subtypes and conditions that might be associated with it.
- ✓ Knowing intervention approaches and conditions need to be considered when choosing intervention.
- ✓ Knowing diagnostic process.

The majority reported more than one lesson obtained from the same session. For example, one mother said 'I have learned from the session what is autism, its types, its causes, its diagnosis in an easy and simple way; I also learned the most important intervention approaches that might help a child'. In term of difficulties and dislikes, 8 mothers said that they did not have any difficulties or dislikes that related to the second session and 1 of them justified that by saying 'no difficulties because all the means used and trainer style of teaching ease the delivery of the information'. However, there were 4 mothers that encountered some difficulties related to the amount of information presented, making it difficult to relate them together or absorb the information, as one mother said 'I felt unable to establish an understanding'. This might be due to the huge amount of presented information. 'I felt tired because the children' exams coincided with the training time' was another difficulty reported by one mother.

Indeed, one can anticipate that the mothers' difficulty in establishing a clear understanding might be due to the rigid nature of the presented and discussed information. As stated earlier, the session is informative and the provided

information was almost scientific and theoretically based on explaining autism as a difficulty in terms of its nature, causes and methods of treatment. Another interpretation could be related to the diversity of the educational level of the mothers who were attending the training as some of them were at middle school level. Possibly, the current training time constraints could be seen as another factor that limited the opportunity to re-explain the presented information to the mothers. Additionally, difficulties the mothers' encountered in relation to the presented information could be also linked to two mothers' responses to questions regarding what they dislike about the session and suggestions for improvement. For example, one of the respondents said 'Speeding up the presentation of the lecture, and did not answer the audience questions adequately' and the other one answered 'time constrains' as the thing she disliked within the session.

Providing more courses like this was three mothers suggestion. Another mother suggested that assigning extra time at the end of the session to answer the mothers' questions. The majority of the mothers stated their desire to obtain more information within the next sessions on:

- Information on intervention approaches and their implementations examples (sensory integration therapy, PECS, dietary intervention, Behaviour management).
- Cases of autism and how it was being treated.

Based on the previous examples of the mothers' responses regarding second session, one would anticipate that the session met its targeted objectives in gaining a clear understanding about autism concepts, its causes and appropriate intervention methods. Indeed, almost all of the mothers' responses were between strongly agree and agree options. Moreover, the strongly agree were more likely the mothers' choice compared to the agree option. In addition, there was consistency in terms of the mothers' response between the first and second part of the evaluation form. For instance, the first part of the form examined the mothers' satisfaction regarding the usefulness, organisation and presentation of the provided information and skills. Thus, the mothers' satisfaction was also reported within the second part. However and regardless that there were four mothers who

reported their dislikes or difficulties encountered throughout the session, most mothers expressed their satisfaction and desire to obtain information and skills within the next sessions. This might suggest that the mothers are getting more specific in relation to the kind of information and skills that they are looking for.

#### 6.4.1.3 Third Session

This session was a combination of providing the mothers with information related to autism resultant problems on the child's growth and the practical applications to facilitate the mothers' understanding to the provided information and skills. Thus, in response to statements that examined the session objectives all 9 responses strongly agreed that the meeting was generally useful (Statement 1) and 8 out of 9 responses showed the mothers' strong agreement that the goals of the meeting were clear, only one participant agreed to that statement. (Statement 2). Seven out of nine mothers were strongly agreed that meetings' goals have been organised and discussed in an easy and logical way while only 2 agreed (Statement 3). In terms of whether the meeting's objectives have been achieved 6 out of 9 mothers strongly agreed, where 3 mothers agreed with the statement (Statement 4).

Almost all responses, 8 out of 9 were strongly agreed that the information that was presented and discussed was important to them (Statement 5) and 7 out of 9 strongly agreed that the applied exercises helped them to acquire the information and the skills related to the training objectives (Statement 6). Only one mother agreed on the importance of the information and two agreed on the usefulness of the exercises. The mothers' replies to the five statements that aimed to examine the session delivery approach (Statements 9, 10, 11, 12 & 13) showed that all 9 received the response strongly agreed on their satisfaction regarding the coach's performance (Statement 9) and 7 out of 9 strongly agreed that the way the information was presented is appropriate to the content whereas two mothers agreed on that statement (Statement 10). In response to statement that the coach was confident in discussing scientific material, 7 out of 9 strongly agreed and 2 agreed with the statement (Statement 11). All 9 received replies strongly agreed that the coach responded to the audience's questions in an effective manner

(Statement 12). Two mothers agreed that the printed material was useful and organised and the rest, 7 responses, strongly agreed (Statement 13).

When the mothers were asked if they intend to apply what they learned in everyday situations 3 out of 9 were agreed and 6 strongly agreed (Statement 7). The majority of the mothers, 7 out of 9, agreed that they are confident that the skills learned in training could be applied at home, and 2 mothers strongly agreed to that statement (Statement 8).

Interpreting the mothers' responses to the second part of the evaluation sheet, where the mothers expressed their opinion over, what they learned from the session? Dislike or difficulties encountered during the session? And information they wish to obtain or suggestion for improvement? Almost all of the mothers, 8 out of 9, reported that they learned from the session the following:

- ✓ The ability to observe the child's behaviour and read its causes.
- ✓ The ability to observe the child's growth and determine the child's strengths and weaknesses.
- ✓ Understand autism effects on the child's development.
- ✓ The effects of positive emotional experiences on enhancing the child's social and emotional development.

The mothers' responses were presented according to its frequency in term of what they learned: Indeed, the majority reported more than one lesson was obtained from the same session. For example, five mothers emphasized that their skill in observing and understanding the child's behaviour and its causes have improved. A number of the mothers reported that they acquired an understanding of autism resultant problems on the child's development and the role of positive experiences in enhancing emotional and social growth.

For example, one mother wrote that 'I have learned from the meeting the relationship between sensory and emotional growth and brain function' and the child being exposed to positive emotional experiences would help in enhancing the child growth'

In term of difficulties and dislikes, none of the mothers reported any particular difficulty or dislikes related to the third session and two of them expressed their satisfactions by saying ‘I liked everything’ and the other one reported ‘I liked the session, the presented information were wonderful and most of them were new to me especially understanding reasons behind the child difficult behaviours’. Indeed, limited comments received from the mothers in relation to the information they desire to acquire and suggestions for improvement. As three mothers stated their desire to obtain more information within the next sessions on:

- How do we maintain our commitment and motivation to educate the child?
- Is the diet part of the treatment and whether it affects the brain function?
- How to manage the child anger and temperament?

Only one mother suggested that ‘I felt that this session should be presented again as the discussed information is mostly new so then one would be able to remember them. She also suggests within the suggestion and enquiry part that ‘providing and discussing more examples of video segments would be useful to prompt the provided information.

Based on previous analysis, the third session met its targeted objectives by providing the mothers with both information and skills simulated with practical applications to make sure that the provided information was acquired. Moreover, in an attempt to compare participants’ responses to the first and second part of the form, according to the evaluation, the mothers were satisfied with section components and delivery. It is based on the findings that was stated earlier that almost all the mothers’ responses were between strongly agree and agree options where the strongly agree were the mothers’ choice comparing to agree options. Moreover, the limited comments received on the second part of the evaluation form compared to the previous sessions’ evaluation where the mothers expressed suggestions and desires openly might lead to the same conclusion of the mothers’ satisfaction over this session.

#### 6.4.1.4 Fourth Session

This session could be seen as a continuation to session three which was a combination of both informative and practical approaches that were applied. The aim was in providing the mothers with a set of information related to interventions approaches and way of implementing them at home. Thus, in response to statements that examining session objectives all 6 responses strongly agreed that the meeting was generally useful and the goals of the meeting were clear, 5 out of 6 mothers were strongly agreed that the meetings' goals have been organised and discussed in an easy and logical way, whilst 1 agreed. In terms of whether the meeting's objectives have been achieved, 4 out of 6 mothers strongly agreed where 2 mothers agreed with the statement.

Almost all responses, 5 out of 6, were strongly agreed that the information that was presented and discussed was relatively important (Statement 5) as well as 5 out of 6 strongly agreed that the applied exercises helped them to acquire the information and the skills related to the training objectives (Statement 6). Only one mother agreed on the importance of the information and two agreed on the usefulness of the exercises. The mothers' replies to the five statements (Statements 9,10,11,12,13) that aimed to examine the session delivery approach showed that all 6 received responses strongly agree on their satisfaction regarding the coach's performance (Statement 9), 4 out of 6 strongly agree that the way the information presented is appropriate to the content whereas two mothers agree on that statement (Statement 10). In response to statement that the coach was confident in discussing scientific material, 4 out of 6 strongly agreed and 2 agreed with the statement (Statement 11). All 6 received replies strongly agreed that the coach responded to the audience's questions in an effective manner (Statement 12). Two mothers agreed that printed material was useful and organized and the rest 4 responses strongly agreed (Statement 13).

When the mothers were asked if they intend to apply what they learned in everyday situations 2 out of 6 were agreed and 4 strongly agreed (Statement 7). The majority of the mothers, 4 out of 6, strongly agreed that they are confident

that the skills learned in training could be applied at home, and 2 of the mothers agreed to that statement (Statement 8).

Interpreting the mothers' responses to the second part of the evaluation sheet, where the mothers expressed their opinion of what they learned from the session?, Dislike or difficulties encounter during the session?, and information they wish to obtain or suggestion for improvement? Three mothers reported that they learned from the session the following, respectively:

'I have learned from the session that nothing is impossible with efforts and willing'.

'I have learned from the session how to develop an intervention program and consideration for its success'.

'I am not alone; all mothers have the same concerns and goals, importantly, to have something to offer the child'

In term of difficulties and dislikes none of the mothers reported any particular difficulty or dislikes related to the fourth session. However, some expressed their satisfaction, as for instance 'every single piece of information was helpful and valuable'. Another one said 'Many thanks to you and the efforts that you made for us and our children'. Thus, the previous analysis would illustrate that the fourth session meet its objectives and provided the mothers with both information and skills that come with practical applications to make sure that the provided skills and information are easily acquired. Indeed, as stated earlier that almost all the mothers' responses were between strongly agree and agree options where in which the strongly agree were the mothers' choice compared to the agree options. Anticipation could be made that the mothers were satisfied with both section components and its delivery. This is because no comments received from the mother expressed any difficulties or suggestions for improvement or dislikes on the second part of the evaluation form compared to the previous sessions' evaluation where the mothers expressed suggestions and desires openly.

#### 6.4.1.5 Fifth Session

The session aim was different from previous four sessions in terms of components and delivery. As this session was prepared and presented by a guest

speaker who is a mother of a child with autism and a professional within the autism field at the same time. The aim was provide the mothers with a realistic example linked to their experience. However, the same evaluation form was used to examine the mothers' satisfaction of having such experience. Therefore, in response to statements that examined the session objectives, 4 out of 5 responses strongly agreed that the meeting was generally useful (Statement 1) and goals of the meeting were clear while one mother agreed (Statement 2) to that. 4 out of 5 received responses' were strongly agreed that the meetings' goals have been organised and discussed in an easy and logical way (Statement 3) while one agreed. In terms of whether the meeting's objectives have been achieved (Statement 4) 3 out 5 mothers strongly agreed where 2 mothers agreed with the statement.

Almost all responses, 4 out of 5, were strongly agreed that the information that was presented and discussed was important to them (Statement 5). Similarly 4 out of 5 strongly agreed that the applied exercises helped them to acquire the information and the skills related to the training objectives (Statement 6). Only one mother agreed on the importance of the information and the usefulness of the exercises. The mothers' replies to the five statements (Statements 9, 10, 11, 12, & 13) that aimed to examine the session delivery approach showed that all 4 out of 5 received responses strongly agreed on their satisfaction regarding the coach's performance (Statement 9), while one agreed. All 5 responses strongly agreed that the way the information was presented is appropriate to the content (Statement 10). In response to the statement that the coach was confident in discussing scientific material (Statement 11), 4 out of 5 strongly agreed and 1 agreed with the statement. All 5 participants strongly agreed that the coach responded to the audience's questions in an effective manner (Statement 12). Also the five mothers' responses strongly agreed that the printed material was useful and organised (Statement 13).

When the mothers were asked if they intend to apply what they had learned in everyday situations (Statement 7) 1 out of 5 agreed and 4 strongly agreed. The majority of the mothers, 4 out of 5, strongly agreed that they are confident that

the skills learned in training could be applied at home, and 1 mother agreed to that statement (Statement 8).

When interpreting the mothers' responses to the second part of the evaluation sheet, three mothers reported patience, optimism and positivity as lessons learned from the session. One mother said, 'always to be optimistic and expect the best from the child'. Other mother commented 'patience and patience and patience, a positive result would be found one day'. None of the mothers reported any particular difficulty or dislikes related to the fifth session. However, some expressed their thankfulness, for instance one mother said 'I appreciate your great efforts to teach us about our children's conditions'. Expectation could be made that the mothers were satisfied with both the section components and its delivery. This is because no comments received from the mother expressed any difficulties or suggestions for improvement, or dislikes on the second part of the evaluation form compared to the previous sessions' evaluation where the mothers expressed suggestions and desires openly.

#### **6.4.2 Overall evaluation forms**

At the end of the training course, the mothers were asked to complete a comprehensive evaluation form to examine their satisfaction regarding the entire training course. The evaluation form was in three main parts aiming to examine the programme's objectives, information, skills, exercises, and training strategies see Appendix F. Indeed, it is worth pointing out that eight overall evaluation forms were received from participants who managed to complete the training course, keeping in mind that the participant mothers were twelve, divided in two groups with six participants in each group, at the beginning of the training. Accordingly, the results from the entire evaluation will be reported and analysed below. The mothers' responses to the fourteen statements within the evaluation form were confined to strongly agree, agree and rarely, do not know options

#### 6.4.2.1 Component Evaluations

In this part the mothers were asked to answer seven structured questions examining their satisfaction of the programmes' components, objectives, information and skills.

Table 23 Components' Evaluation

Statement	Responses
1. The contents of the program <ul style="list-style-type: none"> <li>○ As expected.</li> <li>○ Better than what I expected.</li> <li>○ Less than what I expected.</li> </ul>	1As expected 7Better than
2. Training program objectives <ul style="list-style-type: none"> <li>○ Met all my needs for the current period to help my child.</li> <li>○ Somewhat met my needs for the current period to help my child.</li> <li>○ Did not meet my needs to help my child in the current period.</li> </ul>	6 all were met 2 somewhat met
3. Information that was presented during the training program: <ul style="list-style-type: none"> <li>○ Helped me gain a clear understanding about autism nature.</li> <li>○ Helped me somewhat gain a clear understanding about autism nature.</li> <li>○ Did not help me gain a clear understanding about autism nature.</li> </ul>	8 Helped
4. Information that was presented during the program in general <ul style="list-style-type: none"> <li>○ Logical and coherent.</li> <li>○ Somewhat logical and coherent.</li> <li>○ Illogical and incoherent.</li> </ul>	8 logical
5. Introduced the idea of the current study and present some results and their relationship to the components of the training program. <ul style="list-style-type: none"> <li>○ Was not important for me.</li> <li>○ Gave me an idea about the reasons for choosing training program Components.</li> <li>○ I cannot determine whether it was important to discuss or not.</li> </ul>	8 Gave an idea
6. Discussing autism as a problematic issue for the mothers in the light of the Qur'an and Sunnah at the beginning of training <ul style="list-style-type: none"> <li>○ Helped me to look at my child problem in a positive way more than ever before.</li> <li>○ Made me feel it's my destiny and no hope to change it.</li> <li>○ Valuable input but not an important requirement in the training program.</li> </ul>	8 Helped
7. Thinking Steps and skill of facing problem positively. <ul style="list-style-type: none"> <li>○ Skills necessary to acquire and discuss within the training program.</li> <li>○ Necessary skills, but I do not see need to discuss it within the training programme.</li> <li>○ Skills are not necessary to acquire or discuss within the training program.</li> </ul>	8Necessary

In response to the first question that tests whether the contents of the program were as expected, better than what I expected or less than what I expected. The

second phrase 'better than what I expected' was the most selected option where 7 mothers went with that option, while one choice only was 'As expected'. The training programme objectives, according to the mothers' choice to the second questions' options, 'met all my needs for the current period to help my child. Whereas, 'somewhat met my needs for the current period to help my child' was the response for two mothers. All the mothers were in agreement to their responses to question three that the presented information 'Helped me gain a clear understanding about autism nature'. Moreover, all participants chose the 'presented information was logical and coherent' to answer question four. The mothers' replies to question five were, that introducing the current study aim and presenting the justification of the training components in the light of the obtained results from the interviews and questionnaires, gave them an idea about the reasons for choosing the training programmes' components. In question six, all participants selected the first choice that discussing autism as a problematic issue for the mothers in the light of the Qur'an and Sunnah at the beginning of training, helped them to look at the child's problem in a more positive way than ever before. Question seven tests the mothers' satisfaction of discussing the thinking steps and skills of facing the problem positively as part of the training programme components. The mothers' answers confirmed the importance of discussing such skills, as all of the mothers chose option one, 'Skills necessary to acquire and discuss within the training program'.

#### 6.4.2.2 Second Part of Components Evaluation

Within the second part of the evaluation form, participants were asked to respond to five main questions, 8 to 12, in which each question was followed by a sub-statement to be ranked in relation to the main question according to a five-point Likert-type rating scale, that ranged from strongly agree to strongly disagree. The questions were also examining the mothers' satisfaction over the programme components and its delivery approach. The following tables and discussion will illustrate each main question and the mother's responses to the subsequent attached statements to the main question.

Table 24 Component Evaluation Results

	<b>Question 8: Rate the following statements to be consistent with your point of view.</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
	<b>Statement</b>					
<b>1</b>	The training program did not provide me with any solution to meet my needs.				2 responses	6 responses
<b>2</b>	The training program did not give me any solutions to meet my child's needs.				2 responses	6 responses
<b>3</b>	The training program helped me to understand my child problem.	5 responses	3 responses			
<b>4</b>	The training program helped me to identify my child's goals and to develop an intervention plan	6 responses	2 responses			
<b>5</b>	Training helped me to gain observation skills to note my child's behaviour and try to understand its causes.	6 responses	2 responses			
<b>6</b>	I have been able to observe my behaviour and its impact on my child.	6 responses	2 responses			
<b>7</b>	After training, I gain more confidence in my ability to help my child in the simplest way.	5 responses	3 responses			
<b>8</b>	I would recommend this training to other mothers.	7 responses	1 response			
<b>9</b>	The coach used well prepared training material.	7 responses	1 response			
<b>10</b>	Coach provided good information.	7 responses	1 response			
<b>11</b>	Coach responded to audience's questions effectively.	8 responses				
<b>12</b>	Coach was able to use good examples to clarify the information.	8 responses				
<b>13</b>	Printed materials can be kept as references.	5 responses	2 responses			1 responses

The previous table (Table 26) demonstrated the mothers' responses to question eight. The aim of this question was to examine the programme's components and its delivery approach in general. Indeed, the mothers' responses to the first and

second statements showed that the majority of the mothers strongly disagreed with the assumption that the program did not provide any solutions to enable the mother to meet both her needs and the child's needs, while two disagreed. Statements 3,4,5,6 and 7 were examining the programme's components in providing the mothers with information, skills and empowerment. Thus, the strongly agree options were the most selected choice by the participants, followed by the agree option, to express their opinion that the programme was effective in providing the mothers with the information, the skills and the empowerment. The mothers' satisfaction regarding the programme delivery approach was examined in Statements 8 to 13. Similarly, the majority of the mothers were strongly agreed that the trainer prepared and provided useful information through printed materials and examples and she was able to respond to the mothers' inquiries effectively. A small number of participants agreed with that and only one mother strongly disagreed on the usefulness of the printed materials. The previous result might lead one to anticipate that the participants were satisfied with the training components and happy with its delivery. The mothers' responses to Statement eight, where 7 out of 8 mothers strongly agreed to recommend the programme to other mothers and only one mother agreed; this could be considered as evidence to support the assumption of their satisfaction regarding the training course.

Question nine was attempting to test the mothers' attitude after being exposed to the current training course. Based on the mothers' responses to the fourteen statements that related to the main question with strongly agree, it could be assumed that the program has helped the mothers to adopt positive attitudes and ideas in relation to their role of parenting a child with autism. The basis for this assumption is that the vast majority of the mothers were strongly agreed and a small number of the mothers agreed to the statements, while none of them disagreed to any statements. Thus, such agreement in the mothers' answers would suggest that one of the main aims of the parental training courses in providing the mothers with assistance and self-empowerment was achieved. The following table (Table 27) shows the number of responses to each statement of question nine.

Table 25 Likert Evaluation of Training

<b>Question 9: Training helped me to adopt the following ideas and attitude:</b>		<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>1</b>	Training my child is a legitimate and as a parent, I have the right to demand it.	7 responses	1 responses			
<b>2</b>	My goal is to help my child to his/her maximum ability and not to change him/her.	6 responses	2 responses			
<b>3</b>	My child is capable of learning according to his/her abilities and capacities.	5 responses	3 responses			
<b>4</b>	I am optimistic, yet realistic in my perception and expectation of my child's future.	5 responses	3 responses			
<b>5</b>	My child understands me and sympathises but lacks the ability to express his /her feelings.	6 responses	2 responses			
<b>6</b>	My child is not responsible for unrealistic image that parents or society might hold over him/her, as s/he is equipped with certain capabilities that must be dealt with accordingly.	6 responses	2 responses			
<b>7</b>	I understand that it is possible to reduce the probability that my child might develop any future disorder or psychological damage resulting from failure to satisfy his/her mental, emotional, social and cognitive needs.	5 responses	3 responses			
<b>8</b>	I understand that family's role in enhancing the child's development is more important than specialist's role.	7 responses	1 responses			
<b>9</b>	It is my responsibility to demand my child's rights.	6 responses	2 responses			
<b>10</b>	Everyday situations are an effective way to train my child if it's invested flexibly and creatively.	6 responses	2 responses			
<b>11</b>	I understand that by practicing, putting forth the effort and being flexible while teaching, through the basic skills, I am able to help my child.	7 responses	1 responses			
<b>12</b>	I understand that organizing my child's time and exposing him /her to a variety of activities is important to stimulate growth.	7 responses	1 responses			
<b>13</b>	I understand that by organizing my child's time and exposing him /her to a variety of activities helps in reducing hyperactivity and challenging behaviour.	5 responses	3 responses			
<b>14</b>	My child's current training increases his /her chances to adapt in the future.	5 responses	3 responses			

Twenty-one detailed statements covering various aspects of the course's curriculum were used in relation to questions 10, 11 and 12, where, question 10 was examining the usefulness of the course's components, question 11 was focusing on the importance of those components and question 12 was testing the components' clarity to the mothers. In other words, question 12 was examining the teaching approach while 10 and 11 concentrated on components. Tables 28, 29 and 30 are an illustration of the mothers' responses to these questions. Thus, great similarities were observed in the mothers' responses to those questions through reflective reading. Therefore, the mothers' satisfaction could be expected. This assumption is based on the fact that most responses were strongly agree or strongly disagree to the statement according to the questions' formula to whether the clause is accept or reject. Indeed, both opinions, strongly agree and strongly disagree, reflected the mothers' satisfaction.

'Knowing how to diagnose autism and the diagnostic criteria' was ranked twice with the 'do not know option', one time in response to question 10, the importance of discussing this topic to the mother, and another time in response to question 11, it is better to avoid discussing this topic in future training. Moreover, 'Knowing the causes of autism and theories that explain it' was another statement that got one response of agree, with that it is better to avoid discussing this topic in future training. In question 12 the statements 'Recognizing the importance of play as a training vehicle to stimulate the growth of brain function' and 'Knowing social story technique and how to use it as a mean of intervention approach to train the child' also received a 'do not know' answer. All of these responses were reported by the same participant, whereas there were no other similar responses from the other participants in relation to these statements. Indeed the previous mother's opinion could be referred to personal reasons which in turn made it difficult to anticipate the explanations behind her choices as the forms were anonymous.

Table 26 Evaluation of Importance of Topics

<b>Question 10: The following topics were important for me to discuss and clarify during the training:</b>		<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	Acquiring thinking skill.	5 responses	3 responses			
2	Discussing autism problem in the light of the Qur'an and Sunnah.	7 responses	1 responses			
3	Discussing the family role in claiming their rights.	8 responses				
4	Protecting the family from separation and loss.	7 responses	1 responses			
5	Comparing the family's role to specialist's role.	4 responses	4 responses			
6	Defining autism, and identifying the different types of autism.	5 responses	3 responses			
7	Knowing how to diagnose autism and the diagnostic criteria.	5 responses	2 responses	1 responses		
8	Knowing the causes of autism and theories that explain it.	4 responses	4 responses			
9	Knowing the most effective types of intervention.	6 responses	2 responses			
10	Knowing conditions that should be considered in choosing the intervention.	6 responses	2 responses			
11	Identifying the traits of autism and comparing it to various stages of growth and brain function.	6 responses	2 responses			
12	Knowing the importance of sensory and motor input in stimulating the growth of brain function.	7 responses	1 responses			
13	Recognizing the importance of positive emotional experience and its role in stimulating the growth of brain function.	7 responses	1 responses			
14	Learning how to observe and identify my child's strengths and weaknesses, through observing sensory responses and behaviour, to determine the child level of functional performance.	7 responses	1 responses			
15	Learning how to identify and prioritize training objectives through collected observations on my child.	8 responses				
16	Learning how to develop, evaluate and modify home-based intervention plan.	7 responses	1 responses			
17	Learning how to apply behavioural intervention and analysis main objective to small training steps.	8 responses				
18	Recognizing the importance of play as a training vehicle to stimulate the growth of brain function.	7 responses	1 responses			
19	Knowing social story technique and how to use it as a mean of intervention approach to train the child.	7 responses	1 responses			
20	Discussing some time management solutions and ideas for the mother.	7 responses	1 responses			
21	Discussing some time management solutions and ideas for the child.	7 responses	1 responses			

Table 27 Evaluation of Topics to Be Avoided

<b>Statement 11: In my opinion, it is better to avoid discussing the following topics with other trainees because they are not important for the mothers.</b>		<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	Acquiring thinking skill.				2 responses	6 responses
2	Discussing autism problem in the light of the Qur'an and Sunnah.				3 responses	5 responses
3	Discussing the family role in claiming their rights.				2 responses	6 responses
4	Protecting the family from separation and loss.				3 responses	5 responses
5	Comparing the family's role to specialist's role.				3 responses	5 responses
6	Defining autism, and identifying the different types of autism.				4 responses	4 responses
7	Knowing how to diagnose autism and the diagnostic criteria.			1 responses	3 responses	4 responses
8	Knowing the causes of autism and theories that explain it.		1 responses		2 responses	5 responses
9	Knowing the most effective types of intervention.				1 responses	7 responses
10	Knowing conditions that should be considered in choosing the intervention.				1 responses	7 responses
11	Identifying the traits of autism and comparing it to various stages of growth and brain function.				1 responses	7 responses
12	Knowing the importance of sensory and motor input in stimulating the growth of brain function.					8 responses
13	Recognizing the importance of positive emotional experience and its role in stimulating the growth of brain function.				1 responses	7 responses
14	Learning how to observe and identify my child's strengths and weaknesses, through observing sensory responses and behaviour, to determine the child level of functional performance.					8 responses
15	Learning how to identify and prioritize training objectives through collected observations on my child.				2 responses	6 responses
16	Learning how to develop, evaluate and modify home-based intervention plan.				2 responses	6 responses
17	Learning how to apply behavioural intervention and analysis main objective to small training steps.				1 responses	7 responses
18	Recognizing the importance of play as a training vehicle to stimulate the growth of brain function.					8 responses
19	Knowing social story technique and how to use it as a mean of intervention approach to train the child.				1 responses	7 responses
20	Discussing some time management solutions and ideas for the mother.				1 responses	7 responses
21	Discussing some time management solutions and ideas for the child.				1 responses	7 responses

Table 28 Evaluation of Clarity of the Topics

<b>Statement 12: The following topics were not clear to me.</b>		<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	Acquiring thinking skill.				1	7
2	Discussing autism problem in the light of Quran and Sunnah.				1	7
3	Discussing the family role in claiming their rights.				2	6
4	Protecting the family from separation and loss.				1	7
5	Comparing the family's role to specialist's role.				2	6
6	Defining autism, and identifying the different types of autism.				2	6
7	Knowing how to diagnose autism and the diagnostic criteria.				4	4
8	Knowing the causes of autism and theories that explain it.				3	5
9	Knowing the most effective types of intervention.				2	6
10	Knowing conditions that should be considered in choosing the intervention.				3	5
11	Identifying the traits of autism and comparing it to various stages of growth and brain function.				2	6
12	Knowing the importance of sensory and motor input in stimulating the growth of brain function.				2	6
13	Recognizing the importance of positive emotional experience and its role in stimulating the growth of brain function.				3	5
14	Learning how to observe and identify my child's strengths and weaknesses, through observing sensory responses and behaviours, to determine child level of functional performance.				3	5
15	Learning how to identify and prioritize training objectives through collected observations on my child.				2	6
16	Learning how to develop, evaluate and modify home-based intervention plan.				3	5
17	Learning how to apply behavioral intervention and analysis main objective to small training steps.				2	6
18	Recognizing the importance of play as a training vehicle to stimulate the growth of brain function.			1	2	5
19	Knowing social story technique and how to use it as a mean of intervention approach to train child.			1	3	4
20	Discussing some time management solutions and ideas for the mother.				3	5
21	Discussing some time management solutions and ideas for the child.				3	5

### 6.4.2.3 Open Questions

Within the third part of the evaluation form, participants were asked to respond to two open questions. Question 13 was about the training duration and timing. Thus, in response to question 13 the majority of mothers, 6 out of 8, felt that the training time and duration were ok. Two mothers commented that ‘two days a week were adequate to have benefited from the various information that had been presented’, the other participant said ‘Overall, the time is sufficient to get important information’; however, I would prefer a longer time to practice’. For those who felt that the course was short in its duration, they justified their opinion in the following statements, as one of them said, ‘autism as a topic needs more than the specified time, also mothers need practical implementation on their children in the light of what we have studied with the coach’s supervision’. Similarly, another participant raised the same issue regarding the course length, she expressed her view by saying, ‘after each meeting, we need more discussion along with practical implementation on our children’.

Question 14 was about suggestions for improvement. Five mothers expressed their suggestions to respond to this question. The following are some quotes gathered from programme evaluation forms:

- ‘See if it possible to increase the duration a little bit so that we can take full advantage’.
- ‘I strongly wish to see more of these courses to the people of autistic children to increase knowledge and reduce the problems faced by children with parents and with the surrounding society’.
- ‘To increase awareness of autism in the community’.
- ‘Provide more of these training sessions because of its benefit and usefulness to both the child and the mother, especially since the mother may lack information on autism, after the time of diagnosis in which she may be under the influence of shock and confusion. I would also suggest allocating some of the meetings for fathers, so they may know their roles, the role of family in general and to be sympathetic to the mothers ‘pain and suffering’. In fact, this course had a big role on, what I think, to all of us in relieving stress and venting our feelings and problems’.
- ‘I wish that each mother is blessed with the great opportunity, such as what I had by attending this course. Indeed, many things became clear to us through the training, I

think, the mother's awareness is the condition to the child's progress and if the mother gains self- confidence then her ability to help her child would increase.

The mothers' comments on the course duration were positive. However, three comments in increasing the course length were received as all three mothers raised the same issue of having extra time to practice the learned skills and information on their children directly under the coach's supervision. According to them this would lead to acquire and generalise the learned skills. No negative comments were received that would express the mothers dissatisfaction regarding the course curriculum or the delivery approach. No suggestions or advice should be taken into account in future training were given after course completion in relation to information, skills, and teaching approach. Only coaching sessions that gather both the child and the mother were missing within the current training programme according to the mothers.

## **6.5 Summary of Session's Evaluations and Entire Evaluation Main Findings**

As previously illustrated positive responses were received generally in both types of evaluation forms. No negative comments regarding components or delivery approach were received. Some suggestions of the mothers' interest in acquiring information on specific intervention approaches such as the Applied Behavioural Analysis-ABA were considered and added to curriculum. However, to gain deep understanding a consistency, comparison of both evaluation forms findings were applied with an attempt to follow the current study approach, the constructive grounded theory. As stated earlier both forms have same aim, which was examining the mothers' satisfaction regarding programme components and its delivery approach in meeting the mothers' needs to accommodate their children who were recently diagnosed with autism. The only difference between both forms was that the sessions' evaluation responses were used for on-going programme improvement during the implementation process. However, both evaluation forms responses will be considered in future courses. Consequently, the following results were obtained in term of similarities and differences between both forms.

### 6.5.1 Similarities:

- Positive replies were received in general regarding both programme components and its delivery approach in which most responses confined to 'strongly agree' 'agree' or 'strongly disagree', 'disagree' to whether the clause to accept or reject.
- Individually, there was a limited number of 'do not know' answers reported in comparison to the overall satisfactory answers that been reported by the mothers.
- Providing more time for discussions after each session was occasionally reported by the mothers.
- Providing coach session for the mothers and the children were mentioned.
- Providing training session for fathers were also reported twice one on session evaluation and one in overall evaluation.
- Providing similar courses to the mothers on a regular basis were suggested.

### 6.5.2 Differences

- ✓ 'Do not know' responses were reported on both evaluation forms. In sessions' evaluation it was reported 3 times in correlation with the statements that 'I am confident that the skills learned in training could be applied at home' and that was on the first and second sessions. Differently, in the overall evaluation form 'do not know' was mentioned 4 times associated with specific components of the training programme importance of 'discussing autism diagnostic process and its criteria' and understanding the importance of play therapy and social stories as a mean of intervention.
- ✓ No dissatisfaction responses were reported in the session evaluations' forms while strongly disagree responses were reported regarding the usefulness of the printed materials as well as the statement to avoid discussing autism diagnostic process and its criteria'.

Accordingly, based on previous illustration of the mothers' responses to both forms and the generated view regarding similarities and differences within the mothers' responses, it could be anticipated that the programme components in term of information, skills and empowerment were satisfactory to participant. However, the mothers' comments should be considered to improve future training or instance, providing more time for discussion and coaching. Moreover, maybe the teaching approach to some of the

programme components such as importance of play therapy and social stories as a mean of intervention and discussing autism diagnostic process and its criteria' should be revised and improved.

## **6.6 Parental Stress Index (PSI) Short Form**

The mothers

also completed the parenting stress index-short form pre and post training course as part of the evaluation process. The reader is referred to Chapter four in which a detailed description of this psychometric tool provided in relation to current study aim is thoroughly discussed. The form consists of 36 items to assess parental feelings and experiences in three subscales: Parental distress (PD), parent-child dysfunctional interaction (P-CDI) and difficult child (DC) using a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). The total stress score is an indication of the overall experience of parenting stress where in which the 90<sup>th</sup> percentile score or above represent clinically significant levels of stress (Abidin, 1995). Results obtained from applying the PSI/SF on the mothers pre-training course showed that all participants' scores were in the clinically significant range. Total stress scores obtained were ranging from 166 the highest to 103 the lowest. Analysis of the domain scores suggests that the (DC) domain was the most stressful area with score ranging from 75 the highest to 40 the lowest. This was followed by (PD) with 57 highest score and 33 lowest score. Participants score on (P-CDI) ranged between 52 the highest and 29 the lowest. Indeed, previously obtained results provided the researcher with an indication of stress level of current course's participants before applying the training course. In comparison of obtained data, these findings support the previous mothers' interviews findings that suggested the mothers would need emotional support and empowerment immediately after their children get diagnosed. Consequently, the first session of the training programme was devoted mostly to establish the means for support and empowerment. Indeed, this met the current investigation's main aim in understanding the mothers' needs and suggesting parental training courses to accommodate these needs.

After the parental training course completion, the mothers were asked to complete the PSI/SF. Results showed there were slight reductions but not significant in the mothers' level of stress. Before the course, the total stress scores obtained were ranging from 145

the highest to 102 the lowest. After the course, analysis of the domain scores showed similar results that the (DC) domain was the most stressful area with score ranging from 55 the highest to 36 the lowest. This was followed by (PD) with 47 highest score and 31 lowest score. Participants score on (P-CDI) ranged between 55 the highest and 25 the lowest. The following tables show the profiles of parenting stress reported by parents, pre and post training course. Table (31) provides total scores comparison pre and post training course for each participant. Although participants post total scores were still in the clinically significant range, slight reduction in stress level were identified in 6 out of 8 participants. One of those participants' score decreased from 166 to 102 with 64 scores reduction which could be seen as an acceptable amount of reduction within this context comparing to others whose scores showed a slight drop off. Two mothers' scores were increased but also not significantly.

Table 29 PSI Short Form Results Pre and Post Training

	Pre Total Score	Post Total Score	Difference in score
<b>1</b>	166	102	-64
<b>2</b>	138	145	+ 7
<b>3</b>	133	124	- 8
<b>4</b>	126	121	- 5
<b>5</b>	126	112	-14
<b>6</b>	124	120	-4
<b>7</b>	110	107	-3
<b>8</b>	103	119	+16

Table 30 Pre- Domain Scores

DC	PD	P-CDI
57	57	52
52	47	47
49	46	42
45	46	39
43	44	39
41	34	35
41	33	35
40	33	29

Table 31 Post Domain Scores

DC	PD	P-CDI
52	47	43
46	45	40
45	43	39
44	38	38
43	37	38
41	36	36
39	32	33
36	31	25

The above two tables (32- 33) illustrate both pre and post domains scores considering that it has been arranged according highest to lowest scores obtained. Slight decreased scores were recognized in each domain scores. Although there were no significant decreases in the mothers’ scores totally and in each domain score specifically, there were reductions in scores. Thus, this highlights the importance of providing the mothers of children with autism with such support and help. This support could be seen as an essential requirement where the mothers’ on-going needs might call for further counselling and coaching.

Thus, the previously obtained results were interpreted with caution taking into consideration several reasons; first, examining participants’ satisfaction regarding curriculum components and delivery approach rather than examining training effect on reducing participants’ stress level was the main focus. Applying such a psychometric tool might suggest a holistic notion over establishing, applying and suggesting a method of evaluation that needs to be considered in future investigation to assess such services’ effectiveness. Second, current training helped in educating the mothers about their children’s conditions and existing interventions. However, acquiring such knowledge

does not necessarily lead to a reduction in their stress level. Accordingly, a reduction in the participants' stress level was not expected in the short term duration and only was expected after exposing the mothers to a course of mostly teaching in nature in which the coach would observe the mothers in applying the presented information and skills in the child's natural setting which proved to be impossible due to the time limitations of the current work. Third, it is been widely documented within the literature that parenting a child with autism in general is a very stressful job for parents in comparison to other disabilities (Davis & Carter, 2008). Thus, the post-diagnosed period could be considered as the most stressful period for the mothers due to the difficult feelings such as shock and denial that might emerge as a result of their loved one being diagnosed with autism. In addition, the limited information and skills the mothers experience at that period, which have been identified and discussed previously within the current findings, might illuminate the high stress level the current study sample showed. Therefore, a six weeks course cannot be suggested to solve the problem of autism as providing on-going support for the mothers proved to be essential.

However, the slight reduction in the mothers' stress level within this small sample and short time period might suggest a possible long term reduction if the instructional course is accompanied with parental coaching sessions. In other words, parental needs and accommodating these needs via parental training courses is the main focus of the present study, whereas examining programme effectiveness on parental practice and reduction of stress level would be seen as a following step.

To sum up, a consistent comparison of obtained data from all evaluation methods that were applied to examine participants' satisfaction regarding the course curriculum and its delivery approach might suggest that the current investigation on examining parental experiences to identify their needs immediately after getting the diagnosis and comprising these needs in training course components have been achieved. However, further long term investigations to examine the programme effectiveness in improving parental practice are recommended.

## **6.7 Conclusion:**

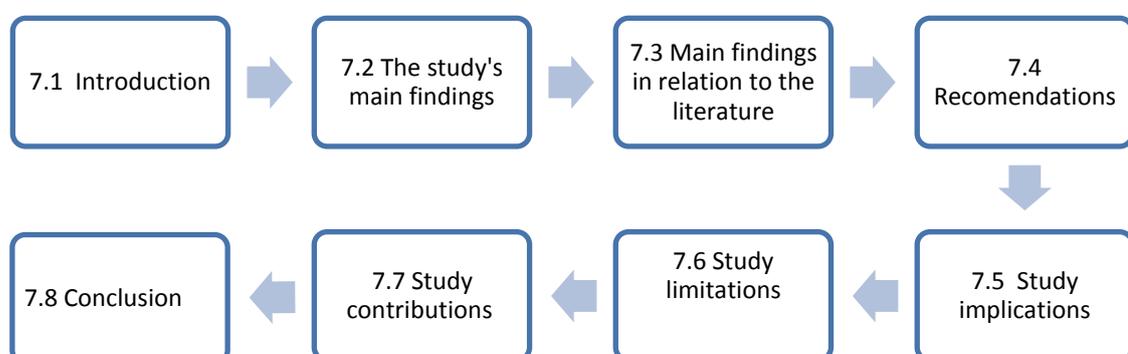
To conclude, this chapter described how the current training programme was designed, taking into consideration the participants' needs and characteristics, cultural context, researcher's role as programme designer and facilitator, and adult learning theories. This consideration was exemplified within the planning steps that have been undertaken to design and deliver the programme's five sessions. Subsequently, the overall process of identifying, designing and delivering the parental training course was evaluated to identify the programme's success in achieving its goal in meeting the participants' needs at the post-diagnosis stage. Each applied evaluation method was discussed in the light of the outcomes and the implications of implementing such a programme on meeting participants' needs and their overall satisfaction.

## Chapter 7: Discussions and Recommendations:

### 7.1 Introduction:

In order to develop a parental training that would lead to an early home-based intervention for children with autism, the study aims to go beyond a focus on the experiences of professionals within the field of autism but to include the voices of the parents and examining their experiences as a result of having a child with autism. Recent recommendations suggest that the voices and perspectives of the parents of children with autism should be included as part of any research process and findings (Webster et al., 2003). In addition, it is believed that many lessons could be learnt from parental experiences in regard to parenting a child with autism (King et al., 2009; Kiltie and Galvin, 2006). Consequently, this study has tried whenever possible to give the individuals' perspectives which should provide some insights of the children with autism and their families by identifying and examining all of the participants' experiences, obstacles, and satisfaction regarding the current provided services and their expectations. Both the Saudi culture and the Islamic perspective on disability have been considered throughout this examination. The amount, depth and extent of the information collected takes into account the reality that such services are in a relatively early stage of development in Saudi Arabia due to the current limited experience of the autism domain generally and in early intervention programmes specifically.

Figure 21 Structure of Chapter Seven



On the basis of the previous illustration of the research main aim and context, this study adopted a constructivist grounded theory approach as a means of investigating the parental experience of having a child with autism. Indeed, a grounded theory approach provides a way of understanding subjective experiences through the systematic and objective analysis (Charmaz, 2004). Several types of research data collection methods were used to gain the study's findings. These were questionnaires, interviews, parental training evaluation's forms and the parental stress index/short form. The study has been guided by a key research question and five sub-questions as follow:

*'How should a parental early intervention training programme be developed in the light of parental understanding of autism nature and parental role in child development within the Saudi context?'*

1. How might a parental training programme be developed?
2. What should the programme components be comprised of?
3. How might a parental training programme be run?
4. What intervention strategies are more effective and are suitable to be implemented with an age group of between two and six years?
5. How could the programme effectiveness be evaluated?

After providing an overview of research rationale and questions, this chapter takes an overall view of the collected evidence that related to the development of the parental training for parents of children with autism in the light of the research questions and links to the literature. The reader is reminded that developing a parental training programme takes into consideration the parents' common and on-going needs as obtained from the findings of the interviews and the questionnaire outcomes, which is central to this thesis. Chapters five and six presented the investigation process and the findings in order to answer the main research question and the sub-questions. Thus, this study has been conducted in three phases. Each phase leads to the following one; Chapter four discussed these phases in details within the methodology process. The discussion of the findings and results of the study phases will be the target of the first part. This is followed by a discussion to illuminate the identified themes in relation to the suggested parental training programme and the literature review. Then, the study's contribution, implications and limitations are provided.

## **7.2 The study's main findings:**

### **Phase one:**

The pilot study was the first phase of current investigation. It attempted to collect evidence related to early intervention programmes for individuals with autism in Saudi Arabia. The aim of this phase was to gain a greater understanding about how such services could be developed. The key results obtained at this stage that especially address gaps in the provisional service provided for children with autism and their families. These include the development of a parental training, the components of the training, the implementation and the evaluation process. Indeed, it was evident that there is a necessity to provide such services due to the limitation of autism provision services in the country as this domain is relatively new and in its infancy stage. Consequently, this study was done in response to filling a gap in the understanding of the development of a parental early intervention training programme within the Saudi context by giving a specific consideration to the parental perspectives. As a result, the pilot study directed the research to what information needs to be acquired and from whom. This in turn has provided an answer to the first sub-question.

### **Phase two:**

In phase two, the semi-structured interviews and questionnaires were developed. Both were targeting two different samples, the questionnaire was developed to cover a general larger sample of parents of children from different age groups with the aim of acquiring their experiences. At the same time, twenty interviews were conducted in order to cover a specific sample which involved only novice mothers with newly diagnosed children with autism, who are between the ages of two and six years and are have not been on any program for more than six months. Thus, a constant comparison of the similarities and differences between the interviews and the questionnaire findings have helped in recognizing the immediate and on-going mothers' needs which in turn helped in determining the parental training programme's components and its designs. These were done to seek and to establish the conceptualization of the parental common and ongoing needs in relation to their children with autism within the Saudi context.

Therefore, three other research's sub-questions (2-3 & 4) were met based on the results acquired through the process of data comparison.

### **7.2.1 The interviews and the questionnaires findings**

The following paragraphs discuss both the interview and questionnaire findings simultaneously in order for the natural outflow of such a discussion which provides a continuity and linkage of all findings. Consistent with a constructivist grounded theory approach and through the constant comparison of the interview and questionnaire findings, the view of the obtained data led to:

- Developed understanding of the surrounding factors that would affect the establishment of the parental training programme.
- Generated a concept of the parental experiences as a result of having a child with autism.

Indeed, developing a parental training aims not only to address the gap in the provision services provided for children with autism and their families in Saudi, but also it aims to equip families with skills and information that would help them to accommodate their children's needs taking into account the parental needs within their cultural context.

#### **7.2.1.1 Difficulties associated with Services**

To the best of my knowledge this study is the first to elicit parental explanatory models of having a child with autism in a Saudi culture. The present study has shown that the majority of the children are diagnosed between the ages of 2 and 5 years old. Therefore, one can conclude that the diagnostic services in Saudi are accessible and children in Saudi Arabia are being identified with autism at an early age. Hypothetically, this early identification should lead to an early provisional input. However, this study does show that only 7% of the questionnaire sample received educational provision when they were under four year old. Those interviewed think that once a diagnosis is given, an appropriate educational provision should be located in order to address the child's difficulties immediately. Yet, this is not the case as public provided provisions are limited and the private ones are expensive. The interviewed mothers felt that the shortages of public provision impacted them in terms of the economic burden of the

treatments and increased their worries about the child's future. This in turn provides an explanation of the high level of stress reported in this study sample.

Both the interview and questionnaire data showed that sources to obtain knowledge and consultation about autism were an issue for concerned parents. Theoretically, professionals should be the first consulted source to obtain knowledge about autism. However, the internet was the parents' first choice to obtain information about autism and its treatments, as 70% of the questionnaire sample reported. In parallel, the majority of the interviewed mothers expressed their dissatisfaction of the professionals' lack in providing information about autism and limited in their expertise and ethical practices. The interviewed mothers felt that they are in disadvantaged situation as a result of inadequate support received from the professionals. Therefore, consulting the internet is an alternative option for the parents. Both the lack of information about autism and the support from the professionals are adding additional stress on the mothers as they reported in the interviews and showed in the clinically significant scores on the PSI/SF.

#### 7.2.1.2 Difficulties associated with the mothers

In an effort to understand the mothers' experiences of having a child newly diagnosed with autism and based on the current study findings of such experiences, a combination of interrelated feelings, understandings and actions must be taken into account. The mother's desire of having a perfect child clashed with the reality that the child is having a problematic incurable condition. The natural sense of the mother's responsibility or the commitment to the child and the concern for his/her well-being is overloaded with a tiring child that requires an enormous effort, not only to provide a normal and enjoyable care but also to understand the child specific needs. All previous feelings and understandings in addition to the mother's hope of finding the ultimate cure to end the child's suffering provides guidelines for the mother's actions in searching and trying any mean of treatment. These attempts might bestow the mothers with some sense of control over their difficulties.

Indeed, through the process of surviving, the mothers developed their own strategies but with minimal external support according to them. The internal feelings of responsibility, the natural love that they hold towards the child along with belief in

God's Will and His Mercy are the tools that nourish the mothers and activate their sense of hope through this difficult time. The data generated from the interviews revealed that faith in God, praying and supplicating to Him were the sources for the mothers' empowerment. Moreover, it has been identified that 'spiritual treatments' are the main strategy that the mothers are using to survive through their journey. It is a mother's source of relief and maintains the hope in finding a cure for the child. The role of faith in people's behaviours and the reasons behind this faith have been discussed in Chapter 2 and examples of the mothers' spiritual behaviours have been identified and discussed extensively in Chapter 5.

At pre diagnosis stage, almost all interviewees and questionnaire participants were aware of their child's developmental delay. Interviewed mothers expressed their feelings of fears that something was wrong with their children which led them to search for an explanation for such abnormalities in the child's behaviour. However, participating mothers expressed specific concerns about the confusion over the diagnosis. Several mothers reported that they were given different diagnoses. This confusion generated the feelings of despair, blame or guilt. The professionals' lack of understanding about autism and their practices might indicate the source of the mothers' complaints. The comments of the participating mothers over the difficulties they encountered at this stage highlighted the importance of getting the right diagnosis, since getting a clear diagnosis would help to understand the child's behaviour, to plan for the future and bring feelings of relief. The anticipation here is that before the diagnosis little can be done to address the child's difficulties.

At the post diagnosis stage, getting the news of having a child with autism and finding out of what is this condition, going through the experience of shock and then facing the reality of autism complexity are the emergent processes of both making sense and surviving the case of the child being diagnosed with autism.

The mothers that participated within this study defined autism differently and attributed its causes to several reasons which have been discussed extensively in Chapter five. Thus, it could be concluded from the variation of autism definitions which have been provided by the mothers that there is some confusion over the notion of autism and how

it affects the child's development. Moreover, the result showed that along with other factors the mothers mentioned that are causes of autism such as genetic or hereditary, both cultural and religious beliefs did affect their attribution to the autism causes. All the mothers believed that having a difficult child is part of their "qadar" (destiny) which should be accepted. Some of them interpret this destiny as a bounty from God whereas others might see it as an examination to their patience and the ability to thanksgiving in good and bad times. In addition, the evil eyes, black magic or evil spirits were mentioned by a number of the mothers. The data also suggested that the mothers' attributions of autism causes have an impact on treatment selection and strategies to deal with the situation. Results showed that parents expose their children to a host of treatments. These include mixed strategies of exposing a child to an educational intervention, complementary alternative approaches such as vitamin supplements or special diet along with practicing 'spiritual treatment' themselves or seeking it from religious people. From the mothers' explanations, it appears that the three different treatment approaches co-exist without conflict, as each approach serves a different purpose in which the mothers think that educational intervention enhances the child's cognition, a dietary approach helps healthy growth and spiritual treatments heal the evil eye or evil spirits. Chapter 2 provide an explanation of such spiritual treatments and the motives behind them within the context of the Saudi culture where examples of spiritual treatment practices within the context of the mothers' experiences of having a child with autism were provided in Chapter 5.

The current results also demonstrated that autism impacts the mothers in several aspects. The social pressures and having difficulties exposing a child to the real world and various activities including family gathering or trips and religious celebrations was one aspect. Losing confidence in parenting a child is another impact identified in the current research findings where this feeling was expressed in questionnaires, interviews and some responses to the training evaluation forms. The interviewed mothers also felt that managing their time between family responsibilities, having normal social activities and caring of the child with specific needs is very difficult. All these factors also provide an explanation of high stress level current study sample experience. Worries about the child's future also could be seen as one of the impact factors that affect the mothers. However, interviewed mothers believe that everything is in God's Hands and

according to His Will. Accordingly, they trust and assume the good future based on that faith.

The previously discussed findings suggest that the mothers make an enormous effort to develop their own strategies to adjust to the child's situation. However, generated findings also showed that the mothers needed to develop their parenting practises to fit the child specific needs. For example, interviewed mothers felt that raising children with autism not only needs extra effort, but also special ways of handling them. They reported that they are trying themselves to improve their skills; however, and according to their views getting support would ease the process of identifying and acquiring the right skills.

Therefore, and based on this generated understanding of the mothers' explanatory model of their experience of having a child with autism, the current parental training has been designed and delivered especially since the mothers' efforts are rich and could be used as a source to feed the development and to provide such services. In addition, these efforts could be enhanced and the mothers would be empowered via such parental training services. Consequently, the data indicated a clear framework of the developmental process of a parental training programme that would lead to an early intervention of a home-based programme in the light of the parental understanding of autism nature and the parental role in child development within the Saudi context. The suggested framework consists of the training programme components, the delivery approach and the evaluation process. A full description of suggested framework has been provided in Chapter six.

Moreover, the importance of Islam has been central to the design and the delivery of the whole training programme, the recruitments of the mothers and the ethical procedures followed to design and conduct of the study. Several examples could be referred to which would exemplify the role of Islamic perspective in designing the programme such as the Prophetic narrations that has been quoted in the questionnaire schedule (see appendix (B)). Another key example and central to the current study could be found in the first session of the parental training. This session is unique in its components in terms of discussing autism as a difficulty in the light of the Qur'an and Sunnah to

stimulate and enhance the mothers' positive emotions and attitudes toward the autistic child. In Chapter 6, the Parental Training Programme provided a details description of this session components and its objectives. The session was the longest session in the whole programme. It was covered in four meetings through two weeks time as it covers the parental needs within its contextual perspective; in other words, the 'Islamic and cultural context'.

### **Phase three**

Thirdly, the last phase of the current study was the implementation and evaluation of the programme. The programme was designed to be conducted in five main sessions which were divided into six weeks for two hours a day, two days a week with a total of 24 hours. Two methods were used to evaluate the training programme: the evaluation forms (session evaluation forms, and overall evaluation form) that been developed by the researcher and the PSI/SF (parent stress index short form) the psychometric tool. The data generated from session's evaluation forms (see appendix (E)) and the overall evaluation forms (see appendix (F)) show high level of the mothers' satisfaction over the parental training course's components and the delivery approach; all responses were confined to 'strongly agree', 'agree', 'strongly disagree', 'disagree' to whether the clause to accept or reject. Chapter 6 provided in depth discussion of the evaluation forms results. Indeed, a key interesting finding showed in the session's evaluation forms is that the 'do not know' responses were associated with the mothers' confidence in applying the learned skills in training at home. However, the 'do not know' responses identified on the first and second session only, no 'do not know' responses were identified in the rest of the training sessions. It could be concluded from this result that the mothers' confidence in applying the learned skills in training at home increased with time. This, in turn, indicates the usefulness of the training programme components and its delivery approach in both in helping the mothers to acquire the teaching skills and in enhancing their confidence in applying them at home.

Another interesting result identified which also would provide evidence over the effectiveness of the current suggested parental training for the reduction on the mothers' (PSI-SF) scores was that the generated data revealed that there is a slight reduction on the mothers' stress level. Regardless to the small sample size and short time period, this

result might suggest long term reduction if the training accompanied with coaching parental sessions. Indeed, this is speculative, as this should be addressed and examine in further studies. However, the current evaluation process has suggested a framework to evaluate this training course and the obtained results of such evaluation have provided an answer to the last sub-question.

The previous paragraphs have highlighted the uniqueness of the current investigation in which the study has examined the parental experiences within its cultural context and this understanding has been used in designing and delivering the parental training course. The results from the three study phases emphasize the importance of establishing and providing the parental training course for the parents immediately after getting the diagnosis. The pilot phase showed the lack of existing of such services currently provided for parents. The second phase demonstrated; firstly, parental agreement of the importance of offering parental training services in which 92% of the sampled questionnaires and all those interviewed mothers strongly agreed on its importance. Second, this phase of the study suggested framework guidelines to the establishment of this service. The third phase confirmed the usefulness of such parental training as all participants reported high level of satisfaction over training components and delivery approach. The obtained results from the study three phases have provided an answer to the main research question and suggested a comprehensive parental training framework within the Saudi context.

### **7.3 The Main Findings in Relation to the Literature:**

The study results demonstrated that there is a real need for such parental training services within the Saudi context as indicated from both questionnaire and interviews findings. However, the call for such services is not only limited to the Saudi context, it has been documented to be worldwide in the literature (Nefdt et al., 2010; Shattuck and Grosse, 2007; Dymond et al., 2007; Ingersoll and Dvortcsak, 2006). Consequently, these results have suggested, a framework of the developmental process of a parental training programme that would lead to an early intervention of a home-based programme in the light of parental understanding of autism nature and parental role in child development within the Saudi context. The suggested framework consists of the training programme components, the delivery approach and the evaluation process.

Having said that, the constant comparison of both interviews' and questionnaires' outcomes have been used to identify the training components and its design as these have been retrieved from the three core categories: the difficulties, the actions and the needs. The philosophy behind the emergent of such categories has been based on the idea that identifying a core category that crystallises other categories and forms a pattern of relationship and meaning between them is central to a grounded theory approach (Charmaz, 2006).

Therefore, the process of analysing how the mothers construct their understanding and reactions to their difficulties they face has led to establish a conceptualisation of their understanding and actions. Within the context of the current study, autism is a central difficulty that creates other difficulties, needs and calls for an actions to face such difficulties and fulfil those needs. Each previously identified category and its sub categories characterized the mothers' experiences of having a child with autism as follows:

❖ Difficulties :

- Difficulties related to children having autism
- Difficulties related to the mothers of autistic children
- Difficulties related to services

❖ Actions:

- Actions before getting the diagnosis
- Actions after getting the diagnosis

❖ Needs:

- Needs for information
- Needs for skills
- Needs for emotional support

The process of examining the mothers' experiences of parenting a child with autism has led to identifying their needs. These needs help to determine the appropriate training components. Consequently, this has helped in answering the main research question:

*how should such a programme be developed.* The next sections discuss the suggested parental training framework in relation to the three identified core categories and linking them to the literature.

### **7.3.1 The Training Programme's Components:**

Based on previous illustration, the study's results suggested that despite the fact that parenting a child with autism is a difficult and stressful job for the mothers, with the right support, these mothers would be able to achieve success. This result, indeed, is consistent with what have been identified in the literature in terms of providing the mothers with the right support can and does work since improvements in the children's social/communication skills and parental knowledge and performance have been reported in several reviewed pieces of research (Wong and Kwan 2010; Whittingham and colleagues, 2009; Vismara et al., 2009; McConachie and Diggle, 2007). Since the current study participants were satisfied with the training components, this result demonstrated that there is a real need for such parental services. Indeed, the current study has suggested a parental training framework. This suggested parental training framework exemplifies most of the mothers' obstacles which were reported by almost all of the research participants. Thus, considering that the current training programme is targeting the mothers of newly diagnosed children with autism. Examining the post-diagnosis period was the focus. Indeed, this period's findings suggest a commonality in parents' experiences in confronting their obstacles. Some of these commonalities are listed as follows:

- Look for information about autism.
- Look for information about services.
- Find services.
- Decide on intervention approach.
- Try different intervention approaches at the same time.

Through this process, the mothers had to confront difficulties related to:

#### ➤ **The mothers themselves:**

- Hard feelings associated with the diagnosis.
- Limited information on autism and interventions.
- Limited understanding of autism nature.
- Sense of responsibility associate with confusion on addressing problem.

- Strengths & weaknesses on parental practises
- Mixed of positive & negative feeling toward the child.

➤ **Services:**

- Limited public services
- Expensive private services
- Poor service quality
  - ✓ Professionals' practice dissatisfaction
  - ✓ Lack of interdisciplinary team

Accordingly, the following section will discuss this suggested framework in the light of two related angles. The first one is the studies conducted with the aim of providing parental training programme for parent of individual with autism. The second is the existing provided parental training programme.

### **7.3.2 Studies on Parental Training:**

Indeed, the study's results are consistent with previous studies in terms of the identified difficulties that parents might encounter as a result of having a child with autism. Such difficulties that have been documented in the literature include the child's lack of social and communication skills, the child's lack of self-help skills, restricted parental time due to their commitment to the child along with other responsibilities, lack of appropriate services and limited financial resources (Dillenburger et al., 2010; Osborne and Reed, 2008). Current training components have addressed these needs by providing the mothers with a range of information related to autism nature and intervention approaches, some practical instructions and self-empowerment skills. The following are an illumination of the programme components that reflect the parental needs which have been identified from the study's three emergent themes: difficulties, actions and needs. Both parental difficulties and actions in relation to their children's difficulties call for needs to be met within that context. Therefore, parents' needs are:

- The need for information on:
  - ✓ Autism.
  - ✓ Interventions services.

✓ Intervention approaches.

- The need for Skills on:
  - Time management.
  - Observations.
  - Planning intervention.
  - Utilize parental practises.
  
- The need for Empowerment:
  - Emotional support.
  - Flexible solutions.
  - Self- empowerment.

Comparing the results of the present study in terms of training components with other studies conducted with the aim of providing training for parents of children with autism, many similarities and differences have been identified. As mentioned above, information related to autism nature, intervention approaches, some practical instructions and self-empowerment skills are the main components of current designed training. In terms of the similarities, several studies have been documented in the literature aimed to train parent on applying specific intervention strategies to improve parental practices such as (Pivotal Response Treatment) (Vismara et al., 2009; Nefdt et al., 2010), (Behavioural intervention strategies) (Whittingham and colleagues, 2009). Other studies have focused on teaching parents the utilization of specific skills to enhance the child development such as (joint attention, language skills, communication and social interaction) (Oosterling et al., 2010; Wong and Kwan, 2010). Moreover, providing generic information about autism nature as part of the training components along with other skills has also been identified in the literature (Nefdt et al., 2010).

Although, current parental training curriculum shares with other studies some previously mentioned components, the suggested framework is more comprehensive in term of its elements. It is providing parents with information about autism, child development, and intervention strategies to improve parental practices and the

utilization of some skills to enhance the child's development. Thus, a detailed description of the training components has been discussed previously within Chapter six. Indeed, the comprehensive nature of current suggested parental training programme's components is one of the most important aspect that differentiate it from other parental training studies that been documented in the literature even though they share some similarities. Therefore, it can be pointed out that previous studies were relatively limited in term of providing specific training components whereas the current programme is relatively more varied and comprehensive.

Moreover, unlike the current study that utilizes the perspectives of parents and understands their needs in relation to their children's difficulties in which they use these needs to serve as the basis for the training components. None of the previously mentioned studies have adopted the parental cultural context and parental perspective in terms of their needs when developing the training course. The focus was mainly directed toward teaching specific intervention approaches or examining its impact in enhancing the child's development. Indeed, taking into account cultural influence and parental perspectives in developing current training course could be considered as another important characteristic that distinguish the current program from previous studies found in the literature which aimed to provide a parental training. Accordingly, and based on previous illustration, one can also anticipate that the similarities between the components of this parental training course and those documented in the literature as a valid indication to support such components. Moreover, these shared similarities could be seen as reflection of the professionals' perspective on what support parents should receive in order to help their children especially when considering that this training course is targeting the parental needs from their views on the first place.

### **7.3.3 Existing- Provided Parental Training:**

Indeed, it is now appropriate to look at the findings on the components of the training programme against the background of work conducted by other authors in the field but in other cultural context, for example, referring back in the literature review and revisiting programmes such as the early birds and the options programme. The parental training framework suggested through this study shares some similarities with previously existing

parental training packages. However, there are also differences. For instance, the Early Bird and The Son-Rise programmes provide parents with information about autism along with some intervention techniques that could be applied at home whereas the More Than Words and the Portage programmes focus in providing parents with some skills to enhance the child-family interaction through emphasising on the importance of day-to-day life. Indeed, the most important characteristic of the current suggested parental training on the previous programmes that it has been generated and developed in the light of the parental needs within its cultural context. In addition to the existing provided training developed in the light of current understanding of parental needs from professionals' perspectives and current effective interventions practices. Therefore, the components of the current suggested framework could be seen as being more inclusive and holistic as it covers the informative, the supportive and the teaching aspects at the same time.

Another issue which is worthy of mention is that at this point that the current study takes into consideration both the Saudi culture and the Islamic perspective in designing this training course. Indeed, the importance of understanding parental needs within their belief system have been reported in a study conducted by King and colleagues (2009). They argue that understanding parental beliefs and acknowledging issues related to the spiritual aspects of their life can assist services providers in engaging parents in the intervention process. This understanding was exemplified within the current suggested parental course. As, a whole section was devoted to discuss autism as a difficulty within the context of Islamic value and considering the specificity of the Saudi culture in terms of family role in child development. Indeed, these place a special emphasis on the importance of the uniqueness to this study.

#### **7.3.4 The Delivery Approach:**

This study comes to some similar conclusion as previous work in different cultural contexts. From the Saudi point of view, many of these issues of parental experience appear to be across cultural in some regards. However, the current delivery approach addresses these issues that related to parental experiences somehow differently. The adaptation of the Islamic philosophy reflected the teaching approach whereas every aspect of discussion was approached holding the principles of; first, believing in 'qadar' destiny which means trust in God with the introduction of the reasons and the second, belief in the concept of 'reward' both in the life and the hereafter. Chapter 2 provided a

detailed discussion of Islamic context where Chapter 6 showed the influence of Islamic culture in the design and delivery of the training programme. Along with considering the role of Islamic culture current training delivery approach also adapted several teaching approaches that could be found in most parental training programme. These include the group discussion, the critical reflection along with the implementation of several teaching aids such as the power-point slides, the video clips, the hand-outs and the designed activities. Therefore, the following discussion will consider current delivery approach in the light of the training approaches that been reported in the literature within the context of first the parental training studies and current provided courses.

Indeed, previously mentioned and adapted teaching strategies have been documented in the literature in providing parental training programmes. Some studies have adapted approaches that were based on didactic strategies while others favour the interactive approach or one on one coaching or even a combination of both. Additionally, the literature has shown that some parental training programmes are conducted in a home-setting whereas others might be centre-based. Some take the form of individual training and the other offer group training. For example, both group and individual delivery approaches were used in a study conducted by Whittingham and colleagues (2009) to teach behavioural intervention strategies targeting parenting practice. The Early Bird training programme and More than Words programme also found to apply a mixture of group session and individual home visit. Wong and Kwan (2010) applied the one-on-one coaching approach to teach communication and social interaction for children with autism with the participation of the primary caregivers.

Using teaching aids such as videos and hand-outs are also reported in the literature. For example, Nefdt and colleagues (2010) utilised a DVD along with an accompanying manual covering the Pivotal Response Training (PRT). Their aim was to provide the caregivers with an introductory knowledge and tips to help their children use evidence-based procedures. Similarly, both the Son-Rise programme and More Than Words are applying several teaching aids within their training such as DVD, Power-Point slides, videos clips and lectures. Previously highlighted teaching approaches have proved to be effective teaching strategies that could be applied in providing parental training

programme. Almost all of these studies have reported positive results regarding the effectiveness of the training in helping parents to acquire knowledge and skills in relation to autism and its intervention approaches. Similarly, it is clear that current study participants have enjoyed the learning through the group discussion and the critical reflection with, and from each other experiences.

As previously mentioned the programme covered a total of 24 hours that was divided over a six week period in which each session was two hours a day, two days a week. Indeed, in an attempt to compare this aspect of current training course with what have been documented in the literature which has stated that there is no clear cut pattern that would suggest the training length. The time range was from 12 months maximum (Oosterling et al., 2010) to five days minimum as in The Son-Rise programme. This variation could be due to several reasons which might include training aim, training components and training delivery approach whether it is home-based or centre-based. Therefore, the decision to conduct current training as previously mentioned was based on both the participants' views and the amount of the information to be presented. Yet again, readers are referred to Chapter six where a detailed justification of current training course length and delivery sequence was provided.

### **7.3.5 The Evaluation Process:**

Using the parental stress index/short form (PSI/SF) along with the evaluation forms as a method of evaluating such parental training course has been documented in the literature. The following is an illustration of this usage.

Although, all participants' scores on the PSI/SF were in the clinically significant range of stress level pre and post the training course. The results obtained from the PSI/SF showed that there were slight reductions but not significant in the mothers' level of stress post the training course. Indeed, this is consistent with the literature by documenting that the current study sample is presenting high level of stress (Nefdt et al., 2010; Hoffman et al., 2009; Solomon et al., 2008). Thus, using the same psychometric tool, Davis and Carter (2008) found in their study that the mothers of young children with autism presented high level of stress particularly during the diagnosis period and initiation of intervention services. They also reported that little is

documented in the literature regarding stress level among parents of young newly diagnosed children with autism comparing to those parents of older children who experiencing high level of stress. Therefore, employing such widely used instruments (Zaidman-Zait et al., 2010) to measure parenting stress level with present participated mothers of newly diagnosed children with autism have helped in; first, gaining a close understanding of level of challenging involved in relation to parenting a child newly diagnosed child with autism; second, answering one of the research questions 'how programme effectiveness would be evaluated'.

Indeed, keeping in mind that the current investigation focuses on examining identified training components in meeting parental needs rather than examining the training effect on reducing participants' stress level. However, the slight reduction in the mothers' stress level within this small sample and short time period might suggest a possible long term reduction. Therefore, this result suggests that the high stress level of the mothers of children with autism should be considered when designing such parental course. Speculatively, high levels of parental stress may influence the parental practises which in turn would affect the child's development.

In contrast, the findings obtained from both the sessions' evaluation forms and overall evaluation forms showed that there was a high level of parental satisfaction regarding the training components and the delivery approach. Thus, this result extends prior work by adding to a growing body of research that indicates that providing parents with training is essential to both the parents and their children. Regardless to the diversity presented in the literature in terms of programmes' components and their delivery approaches, almost all documented results on both currently provided parental training course and studies conducted with the similar aim of providing parents with training course are promising (Oosterling et al., 2010; Wong and Kwan ,2010; Nefdt et al., 2010; Vismara et al., 2009). Moreover, using the evaluation forms as a method of evaluating such a parental training course has been founded in the literature in several studies, for instance, Pillay et al., (2011), Whittingham et al., (2009) and Ingersoll and Dvortcsak (2006).

Thus, based on the previous illustration where the current study findings were discussed in the light of current literature in both parental training and early intervention services, several conclusions can be drawn that would relate the outcomes of this study to the most recent evidence from the research literature.

First, as found in previous studies parental training programmes appear to be helpful at a number of levels for parents of children with autism in terms of providing information, tangible intervention strategies and boosting parental confidence (Vismara et al., 2009; Whittingham and colleagues, 2009; Nefdt et al., 2010; Oosterling et al., 2010; Wong and Kwan, 2010). Therefore, the results of this study clearly indicate that with the careful investigating of the parental needs in relation to their experiences of parenting a child with autism, it is possible to develop a parental training course and determine both its components and delivery approach that aimed to meet such needs.

Second, an important feature of the current suggested parental training relates to the parental perception of the type of support and help that they expect to receive. Christie and Chandler (2002) argue that parents have their own views of the types of support that they value. The mothers' satisfaction with the programme components and its delivery approach in meeting their needs are met as the current investigation suggests that parental input is a valuable resource that needs to be considered. This in turn addresses the gap in the literature of the importance of taking into account the parental input in providing support services (Kling et al., 2010; Meirsschaut et al., 2010).

Third, the study result in terms of developing and providing a parental training course that targets parents of individuals with autism, addresses the shortage of such services that should be available to parents. As such, services that have been documented in the literature are a scarcity, where currently provided services generally target the individuals with autism themselves, rather than their parents (Carpenter, 2007; Dymond et al., 2007; Coolican et al., 2010).

## 7.4 Recommendations

The above research has examined the parental experiences in relation to parenting a child with autism. The results obtained suggested a parental training programme framework. Thus, it is appropriate now to make some recommendations which might lead in advancing the 'autism best practices'. Regardless that the current investigation was conducted to fit the Saudi context, the current results have led to some recommendations that could be applied widely. Following are key recommendations that have been generated based on this study implementation and results.

- ✓ *Early intervention* provision should be offered for the children once the parents and the professional suspect that there is a developmental delay regardless to the type of disability. This, in turn, would enhance the child's development as early as possible. Moreover, by exposing a child to intervention at the early stage of suspicion, this would help in reducing the parents' feelings of shock and uncertainty of what they should do to face the problem. It could be expected that early intervention provision at this early stage serve as a first solution that would give the sense of control for parents. Therefore, offering such a service is essential for both the child and parents equally, and within the Saudi context the current suggested parental training framework.
- ✓ *Parental training* service is another form early intervention services that should target the parents of children with autism at the diagnosis stage. Since the pre and post diagnosis stage are difficult periods for the parents, the aim of this service should be to accommodate and provide the parents with both emotional and informational support. The current investigation suggests that providing parental training courses would be more effective if combined with coaching sessions. In addition, providing parental training courses would compensate the limited number of specialist placement that available to accommodate the increasing number of children diagnosed with autism. This, in turn, would provide a child with a chance to expose to intervention at home till s/he obtains the educational placement. Moreover, equipping the parents with skills that enable them to address their children's needs would increase the child's exposure to intervention at home even if s/he obtains the educational placement.
- ✓ *Parental empowerment* is a very critical aspect of services that parents of individuals with autism should receive especially since the current study results

have shown that parents of an individual with autism make an enormous effort to develop their own strategies to help the child. However, the amount of stress they are facing is very high due to the complexity of autism nature and shortages of services. Indeed, this, in turn, might hinder these efforts which should be invested so the best usage can be made. Therefore, parents should be empowered by providing them with consultation and support special during the adjustment process of conceptualizing autism and then deciding on the appropriate treatments.

- ✓ *Parental survey* - parents are the main service consumers. Therefore, seeking their expectations of services that they expect to receive, the kinds of support they are looking for and their satisfaction of current provided services is fairly important. This is for several important reasons: firstly, any provision should be adapted to meet the parental needs. Secondly, parental experiences are rich and could be used as a source to feed the establishment of provisional services or evaluate and improve the existing one.
- ✓ *Cultural context* is an essential factor that influences the parents' understanding and actions in relation to having a child with autism. The results of this study have highlighted the importance of such cultural aspect in dealing with autism as a difficulty. Indeed, the similarities of parental experiences over the autism nature and its treatment might be found cross- cultures; regardless that there are similarities, cultural differences coexist. Therefore, considering the cultural context can assist services providers in engaging parents in the intervention process (King et al., 2009).
- ✓ *Interdisciplinary teams* in which all main services providers such as health, education and social services should work together collaboratively. This collaboration is extremely important in providing planned services to accommodate the children and their families and avoid duplication in providing similar services and facilities. This could be through a multi-agency team in which parents consult one responsible agency instead of referring them from one services provider to another. The multi-agency team should provide comprehensive services (diagnostic, counseling, educational...etc). Indeed, such multi-agency approach it could be beneficial and cost effective in the long term. Moreover, it reduced parental confusion in finding the right services that are

available to them and their children. This, in turn, would limit the possibility of experiencing high level of stress due to the fact that it is parental responsibility solely to help a child and find a solutions to his/her difficulty.

- ✓ *Professional development* programmes need to address parents needs and conditions in its training components as those professionals are expected to work not only with a child with autism but also with their parents. The data in this study has identified that some mothers are dissatisfied with professional practices. Therefore, professionals should be equipped with skills that would enable them to accommodate parental needs. These skills might include the ability to develop a trusting relationship, in addition, the ability to be sensitive and empathetic to parental interpretation of autism and its causes as well as an understanding for the parental desire of finding magical solutions that would end their suffering.

## **7.5 Study implications within the Saudi context**

Chapter 2 provided background information about the development of special needs services in Saudi Arabia. The discussion showed that there are enormous governmental efforts to develop such services. However, obstacles and challenges coexist especially with regards to services provided for individuals with autism and their families. The current investigation showed that there is a shortage in early intervention provision for children with autism. Also, the results showed that only 7% of questionnaire sample received early intervention provision at early age. Indeed, due to the limited number of public autism centers within the country and its limited capacity to accommodate the increasing number of children being diagnosed with autism. The suggested parental training through this study is a step toward establishing an early intervention services and filling the gap in current provided services. This research is the first in its kind to examine parental experiences in relation to their children with autism within Saudi cultural context. Then, the generated knowledge of such experiences was the source to develop the parental training to accommodate the identifying needs.

The study findings sensitise services providers in Saudi to:

- Firstly, adapting the current suggested parental training programme to be one of their services which should be provided for children with autism and their

families once a child been diagnosed as it has been developed based on Saudi culture.

- Secondly, establishing multi-disciplinary team centers to serve the parents as discussed previously within the recommendations section.
- Thirdly, services providers should consider the professionals' development. This could be via providing professionals with training courses on a regular basis to enhance their best practices and update them with recent findings within the field of autism. Another way could be via implementing academic courses on autism in order to prepare qualified people.
- Fourthly, providing parents with parental training courses on a regular basis to update them with the new techniques within the field and to enhance and to empower the parents. Such training should consider parental needs and complaints through the adaptation of customer survey method. The survey should aim to assess parents' satisfaction over the provided services. Therefore, further development and improvement would take place and new services could be established based on parental needs.
- Fifthly, whilst it is important that everything we do to promote the wellbeing and development of young autistic children should involve the whole family, it is nevertheless also important to recognise that, in practice, much of the day-to-day work with the children devolves to the mothers themselves. This is not the most desirable situation but in Saudi Arabia at this time it is the most practical situation (and is not unlike much of the western world). Hence, working with the mothers becomes the pragmatic option for training family members to intervene positively at home with their autistic child. The cultural and religious environment in an Islamic country does, at this point in time, need to recognise that the interface between men and women in a public space has to be treated with due deference to the cultural norms and expectations. Consequently, to progress the work it was necessary for the researcher to be conscious that every effort be taken to ensure that the messages to be conveyed could be done so with minimum discomfort and embarrassment to those who were the recipients of the training. However, service providers could apply additional steps towards confronting such cultural aspects, and provide the fathers with the chance to be involved in the training programme. For instance, in the case of providing a

mixed gender course the parents (mother and father) would have the right to choose whether to attend the mixed gender course or a separated gender training course. Another scenario would be to offer separated gender training programmes, with male instructors for the male recipients and female instructors for the female recipients.

## **7.6 Study Limitations:**

The previously discussed results and contributions are promising; however, this study is not without limitation. The following will highlight some of the limitations related to current investigation.

According to the grounded theory approach, the study sample should be sufficient to generate an in-depth data that represent patterns, concepts and categories of the phenomenon (Glaser and Strauss, 1968). The sample size within this study of 251 questionnaires, 20 interviews and 8 training participants were sufficient to illustrate the concept of parental needs in relation to their children with autism. As Corbin and Strauss (2008) suggest that sample size for grounded theory often ranges from 10 to 30. However, there were some limitations to the research sample. The study sample is not necessarily a representative sample of the population of families of children with autism in Saudi Arabia. For example, the questionnaire's sample covered only three big cities in the kingdom whereas the interviews and the training sample covered only one city. Therefore, results could be seen as an indicative rather than reflective in terms of its number to reflect the entire population of families of children with autism across the kingdom's regions.

Another limitation within the context of the study sample is that both interviewees and training participants were mainly the mothers due to Saudi cultural constrains. Therefore, the fathers' perceptions were absent in current study. Even though this could be seen as one of the study's limitation, however, the attempt to examine the fathers' perspective and participation within the autism literature showed that the fathers' involvement was relatively less than the mothers' involvement even with the absence of cultural constraints. In previous studies such as those conducted by Nefdt et al., (2010) and Whittingham et al., (2009), the fathers' participation was examined less than that of

the mothers whereas other studies (Kishore and Basu, (2011) and Benson et al., (2008)) focussed mainly on the mothers.

Regardless, the findings of this study expanded the existing knowledge by exploring parental experiences of having a child with autism within the Saudi context; some training components that reflect both Islamic perspective and cultural stance might not be applicable to other cultural contexts. Indeed, the Islamic component of the training programme could be applied and generalized to other Islamic cultural. However, the result might inspire other studies to incorporate similar approach that fit other cultural contexts within the training components. Thus, this could be seen as one of the study's strengths and limitation at the same time in which the generalization of the current study needs to be treated with caution.

Parental evaluation forms were the main measure to examine participants' satisfactions in relation to programme components and delivery approach in meeting the mothers' needs. Therefore, the use of the mothers' report as a measure is a limitation to current investigation for two important reasons. Firstly, the obtained results do not ensure that participants have learned and benefitted from the training programme. Secondly, the mothers as the assessor might be influenced by the placebo effect of the training course. For example, the mothers' responses are usually affected by their understanding to the questions and this might include question bias, question misunderstanding, responses truthful and clearness, and intentional deception.

## **7.7 Study Contributions:**

The study complements the constructivist grounded theory approach to the development of the parental training course that would lead to home-based early intervention. The emphasis was on the parental experiences of having a child with autism by considering both Islamic and cultural perspective within the Saudi context. The key discoveries of this study address the gaps in both the literature generally and current provided services within the Saudi context specifically of *how should a parental early intervention training programme be developed*. These discoveries include examining parental

experiences of raising a child with autism; parental understanding of autism nature; parental role in child development; and then suggesting a parental training course framework based on that. The uniqueness and the contribution of current investigation are expressed in the following aspects:

#### **7.7.1 Contribution to the Application:**

The main contribution of this investigation suggests a model of a parental training course and provides a detailed description of its components, delivery approach and evaluation process. This contextual perspective would sensitise services providers to establish a parental training programme by understanding strengths and weaknesses within the parental experiences in relation to their children with autism by reflecting on that. Using this understanding of parental needs, the services providers can provide sensitive services that help parents to administer some of the therapy to their autistic children that is needed on a day to day basis with the minimal amount of stress to the parental life style. Indeed, the greater the understanding of such parental needs, the more likely it is that the training will meet those needs. For example, within the session, evaluation forms' responses were received from the current programme's participants in the first and second sessions with '*do not know*' answer. This answer reflects the mothers' confidence to apply the skills learned in training at home. However, none of the '*do not know*' answers were received within the following third fourth and fifth sessions. This gives an indication that the mothers' confidence increased through the training in relation to their ability in applying the learned skills at home.

Another example that could be reported at this point is within the overall evaluation in which all the mothers reported that the presented information helped them to gain a clear understanding about autism nature. Moreover, the majority, 6 out of 8, reported that the training program objectives met all their needs for the current period to help the child. Therefore, one can anticipate that this study contributes to the development of parental training by considering the needs and interests of the mothers. Kling et al., (2010) and Meirsschaut et al., (2010) argue that successful implementation of family interventions required a consideration of their needs. Thus, this result suggests that the

parental training components and delivery approach led to meeting the identified parental needs from current investigation.

It could be argued; on the basis of these findings, that the parental training could be seen as an alternative choice in the light of limited early intervention provisions available for children with autism and their families within the Saudi context. Moreover, it also could be seen as a warranted choice for some families due to special circumstances such as distance to intervention facilities, long waiting lists or personal preferences. Indeed, the importance of receiving training support on how to deal with children with autism have been reported by several interviewees within this study.

### **7.7.2 Contribution to the Knowledge and Theory:**

To my knowledge, this study is the first study to examine the parental perspective within the Saudi context and to use the obtained knowledge in designing the parental training course. As a result, an entire training session was devoted to inspire positive emotions and attitudes as well as discussing family and the child's right considering the Islamic and cultural stance. Few recent studies addressing parents' experiences of having a child with autism have been documented in the literature with different aims (Kishore and Basu, 2011; Dardennes et al., 2011; King et al., 2009; Shyu et al., 2010; Swanke et al., 2009; Tsai et al., 2008). However, none of them has examined parents' experiences to develop a parental training course within the Saudi context.

The sample's diversity within this study is also another contribution to the field due to the fact that the study sample examines not only novice parents coping with autism for the first time but also those parents who have experienced autism at different stages and receive a range of services. This could be seen as a strong point because it gives a wider picture of needs and what could be an effective support parent should acquire at early age.

### **7.8 Suggestions for further research:**

Although, the mothers reported that they are satisfied with this training, if this research were to be undertaken again, the following points would be added to the approach in order to strengthen it.

Firstly, more Saudi cities should be covered in order to obtain a representative sample of the population of families of children with autism in Saudi Arabia.

Secondly, the mothers' feedbacks should be considered to improve future training for instance, should provide more time for discussion and coaching, revising and improving the teaching approach to some of the programme components such as the importance of play therapy and the social stories as a mean of intervention and discussing autism diagnostic process and its criteria.

Thirdly, subsequent studies should evaluate the impact of the training on the child's development and evaluate parental maintenance and generalization of the provided skills will be recommended by employing arrange of additional well-standardized measures to determine programme effectiveness because this study did not address this. (Suggestions of Pre and Post developmental evaluation to see if there is any improvement)

Fourthly, the cost-effectiveness of implementing such parental training course is unknown. Therefore, future empirical study is needed to evaluate short and long term effects of providing such services within the Saudi context.

Fifthly, future studies should establish training programme for special educators to enhance their ability to teach parents and provide them with coaching strategies to deal with families as identifying parental training framework would call for professionals to be able to apply such framework.

Sixth, future studies should involve more fathers in the process or having joint sessions of the mother and fathers. This was a suggestion of one of the mothers as seen in her comment:

*I would also suggest allocating some of the meetings for fathers to know their roles, the role of family in general and to feel the mothers 'pain and suffering'. In fact, this course had a big role on, what I think, to all of us in relieving stress and venting our feelings and problems'.*

## **Conclusion:**

A primary goal of the present study was to develop a parental training programme that would lead to an early intervention home-based programme which could be implemented immediately following the diagnosis. This study gathered parental experiences of having a child with autism by a qualitative constructivist grounded theory investigation. The aims were to identify and better understand the parents'

common and on-going needs. The findings highlighted the needs for family intervention that considered parental needs and accommodated them. Then, this obtained understanding utilized the development of more supportive parental intervention that would provide the mothers with the necessary information and skills to enhance their parental practices. The present study suggested a parental training course framework with a detailed description of its components, delivery approach and evaluation process. This study also provided clear evidence that the current suggested parental training framework have targeted the participants' needs and provided them with the support, the information and the skills they needed at the post diagnosis stage. As mentioned before, a high level of satisfaction was reported by the mothers, for instance:

*'I wish that each mother has the luck and the great opportunity, such as I had by attending this course. Indeed, many things became clear to us through the training. I think that the mother's awareness is the condition to the child's progress and if the mother learns to trust her ability to help her child, her self -confidence would increase'.*

*'Provide more of these training sessions as they are beneficial and useful to both the child and the mother, especially since the mother may lack information on autism, especially when under the influence of shock and confusion after the diagnosis. I would also suggest allocating some of the meetings for fathers to know their roles, the role of family in general and to feel the mothers 'pain and suffering'. In fact, this course had a big role on, what I think, to all of us in relieving stress and venting our feelings and problems'.*

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## **Appendixes:**

- Appendix: A- Down's syndrome: Early Intervention Programmes Report
- Appendix: B – Questionnaire schedules
- Appendix: C - Interview questions
- Appendix: D: The consent Letter.
- Appendix E: - Parental Training Evaluation Form
- Appendix F: Overall Final Evaluation for the Parental Training Program
- Appendix G: Parenting Stress Index, Short Form
- Appendix H: Sample Exercise and Story
- Appendix I: List of References of Information and Videos
- Appendix J: A brief Description of Autism and Autism Services Booklet

## Appendix: A- Down's syndrome: Early Intervention Programmes Report

### *The programme's objectives*

- To accommodate as many as patients as possible on the waiting list.
- To offer guidance and share experiences for parents to ease their emotional stress and support them during difficult periods.
- To offer intervention as early as possible from birth to preschool.
- To focus on social skills; communication skills and self-help skills using several educational methods.
- To raise societal awareness of the rights of this population so that they can more easily be integrated.

### *Programmes' Implementations*

#### PHASE ONE:

- Home visits by clinicians to support the parents from birth to nine months.
- Arrange for individual sessions; with only mother and child and group sessions with other mothers and children at the centre twice a month from nine months to three years.
- The sessions include the involvement of specialised staff in the fields of physiotherapy; speech and audiology; psychology and nursing.
- Liaise with other centres to accommodate some children due to the limited availability after the first intervention phase.

#### PHASE TWO:

Consists of two levels

- Holding Group One: ages three to four-years. This is the first separation from the parents.
- Children attend morning classes three times a week.
- Holding Group Two: ages four to five years. Children attend morning classes five times a week.

### PHASE THREE:

Pre-school Programme (five to seven years). The bridge between ‘early intervention’ and the advanced classes. Pre-academic skills such as pre-reading, pre-writing and pre-mathematics are introduced

#### *Intervention approaches and programmes:*

- THE BAVARIAN CURRICULUM
- PORTAGE
- MAKATON
- MONTESSORI

The above scheme reflects the importance of running such programmes and their success in Saudi Arabia especially since this programme has been running since 1989. Its existence has motivated me to think about helping in the development of one of the first early intervention programmes for individuals with autism. However the previous interviews and visits could be seen as a diagnostic step to make sure that there is a possibility to undertake research in this specific domain.

## Appendix: B - Questionnaire schedules

Dear Parent,

Asalam alaikum

In a *Sahih Muslim* narration related by Abu Hurayrah (may Allah be pleased with him) that the Messenger of Allah (peace be upon him) said: "When the son of Adam dies, all his deeds ceases to benefit him except three: on-going charity, beneficial knowledge or a righteous son who will pray for him.

The current study aims to develop a parental training course in a home-based early intervention programme for autistic children. The parental training course will provide parents with detailed information about autism and its nature, as well as equipped parents with the necessary skills that would help them to implement the program. In order to develop this program, I am requesting parents to take part by answering a questionnaire. I would be honoured and appreciative for your participation.

Indeed, the design of this program will depend primarily on questionnaires' findings. The questionnaire consists of three main parts (general information, questions, and feedback). Your information and feedback are essential to help further scientific research. I hope you can assist me in collecting information by reading and answering all the questions.

Thank you for your time and consideration. I will wait for your reply.

Should you need further clarification please contact me on the following:

Mobile: **0532592831**

E-mail: [Hiam.Al-Aoufi@brunel.c.uk](mailto:Hiam.Al-Aoufi@brunel.c.uk)

Yours sincerely,

Hiam Alaoufi



Training for independence

Watching TV with my child

Others please specify

17. Do other siblings play or interact with the child?

Yes

no

if yes please give

example

If No why do you

think this happened?

18. Do other siblings take responsibility of the child?

Yes

No

if yes please give

example

If No why do you

think this happened?

19. What kinds of skills do you want your child to acquire at this stage? List three from most to least

20. How do you educate yourself and your family about autism? (you may choose more than one)

Books

TV

professionals

Newspapers

Radio

paediatrician

educationalist

Magazines

Internet

psychologist

social worker

Other please specify.

21. which of the following you find most stressful :

child's Poor language and communication skills

child's Disruptive and bizarre behaviour

child's Weak social awareness

### Part III

Please Rank the following statements

---

Statement	Strongly agree	Agree	Do not know	Disagree	Strongly Disagree
1. My doctor gave me a clear explanation about the nature of autism.					
2. The information my doctor gave to me about available services to support individual with autism has been sufficient.					
3. I am aware of educational interventions that available for children with autism.					
4. I am aware of educational programme that available to parents to develop their support skills.					
5. I am confident that I am able to help and educate my child.					
6. I think that offering a parental training course would help me to deal with and support my child in a professional way at home.					
7. I believe it is solely the role of professional to provide intervention to my child.					
8. Existing Services that currently provided to individual with autism and their families are adequate and helpful.					
9. I understand that there is no cure for autism.					
10. I understand that my child will always need help and support to aid his/ her development.					
11. Living with a child with ASD stressful to mother					
12. Living with a child with ASD stressful to father					
13. Living with a child with ASD stressful to siblings					

---

The questionnaire completed by  Mother  Father  other.....

## **Appendix: C - Interview questions**

- Tell me about your child situation or difficulties?
- How did his /her difficulty make you feel?
- Why do you think you feel that way?
- Imagine that you could go back in time? Did you suspect that your child might have a problem?
- Tell me about your feeling when the doctor told you that your child has autism?
- What were your initial thoughts about autism?
- What lead you to think of autism this way?
- After getting the diagnosis what was your reaction?
- What did you hope to receive at that point?
- How would you compare your family life before and after getting the diagnosis?
- How would you describe your husband's involvement in your child's life?
- Tell me more about what kind of support does he offer?
- What do you think is the relationship between your child and his/her siblings?
- How did your immediate and extended family receive the idea of that your child has autism?
- Tell me more about kind of support they might offer?
- If I ask you to describe your child day. What would you say?
- What kind of support do you expect which you could offer to your child at home?
- How do you see your child's future in the light of the available services?
- Tell me more about your experience of available services?
- Suppose you could design a training program for parents who are in similar situation to you. What would the program component be?

## Appendix: D- The consent Letter.

Dear Mother,

I am a post graduate student at Brunel University. As part of my PhD degree programme, I am conducting a study to investigate issues relating to the development of a parental training course in a home-based early intervention programme for children with autism. As your life focuses around your autistic child, I would like to get your point of view from your parenting experiences in dealing with a child of such disabilities and also get your input on the kinds of support you think that you need. I would be grateful if you would consider being interviewed and to spend some time with me to discuss issues relating to your personal experiences. Moreover, The information collected it would be based on responses from an interview and will be used to develop an 8 week parental training programme course that leads in developing home-based early intervention programme. The interview will be recorded and transcribed for research purposes. I would like to emphasize that should you agree to take part in the study all the information you provide will be treated in the strictest confidence and your participation will be anonymous. Moreover dear carer you have the right to withdraw from the project- or withdraw your data at any time.

I hope you will assist me in my research. I will be honoured and grateful for your participation. Thank you for your time and consideration. I will wait for your reply.

Yours sincerely,

- Agree** to participate in the interview process and parental training programme

Mother's name:

Mother's signature:

- Disagree** to take part.

Mother's name:

Mother's signature:

## Appendix: E - Parental Training Evaluation Form

This form is to provide feedback concerning the parental training programme in order to find areas of improvement.

Part I: Based on your experience, please put a check ( ✓ ) on the answer that applies best expresses your opinion.

	Statement	Strongly agree	Agree	Do not know	Disagree	Strongly disagree
1.	The meeting was generally useful.					
2.	Goals of the meeting were clear.					
3.	Meeting goals have been organized and discuss in an easy and logical way.					
4.	Meeting objectives have been achieved.					
5.	The information that was presented and discussed was important to me.					
6.	Exercises that have been applied helped me to acquire information and skills related to training.					
7.	I intend to apply what I learned in everyday situations.					
8.	I am confident that the skills learned in training could be applied at home. .					
9.	The performance of the coach is good.					
10.	The way the trainer presented the information is appropriate to the content.					
11.	The coach was confident in discussing scientific material.					
12.	The coach responded to the audience's questions in an effective manner.					
13.	The printed material was useful and organized.					
14.	The meeting place was organized and appropriate for training purposes.					



## **Appendix: F - Overall Final Evaluation for the Parental Training Program**

Dear Mother,

Thank you for participating in the parental training programme. I would appreciate if you can take the time to fill out the final evaluation of the parental training programme. Your opinion is considered to be a valuable asset in the development of training programme. If you can please, read the following statements and select the answer that best represents your opinion. Please note, there are no right or wrong answers.

Part I: Please select the answer/s that best complete the statement.

### **8. The contents of the program**

- As expected.
- Better than what I expected.
- Less than what I expected.

### **9. Training program objectives**

- Met all my needs for the current period to help my child.
- Somewhat met my needs for the current period to help my child.
- Did not meet my needs to help my child in the current period.

### **10. Information that was presented during the training program:**

- Helped me gain a clear understanding about autism nature.
- Helped me somewhat gain a clear understanding about autism nature.
- Did not help me gain a clear understanding about autism nature.

### **11. Information that was presented during the program in general**

- Logical and coherent.
- Somewhat logical and coherent.
- Illogical and incoherent.

### **12. Introduced the idea of the current study and present some results and their relationship to the components of the training program.**

- Was not important for me.
- Gave me an idea about the reasons for choosing training program Components.
- I cannot determine whether it was important to discuss or not.

**13. Discussing autism as a problematic issue for mother in the light of the Qur'an and Sunnah at the beginning of training**

- Helped me to look at my child problem in a positive way more than ever before.
- Made me feel it's my destiny and no hope to change it.
- Valuable input but not an important requirement in the training program.

**14. Thinking Steps and skill of facing problem positively.**

- Skills necessary to acquire and discuss within the training program.
- Necessary skills, but I do not see need to discuss it within the training programme.
- Skills are not necessary to acquire or discuss within the training program.

Part II: Please rate each statement for questions 8-12.

**8. Please rate the performance of the training program.**

	Statement	Strongly agree	Agree	Do not know	Disagree	Strongly disagree
1	The training program did not provide me with any solution to meet my needs.					
2	The training program did not give me any solutions to meet my child's needs.					
3	The training program helped me to understand my child problem.					
4	The training program helped me to identify my child's goals and me to develop an intervention plan					
5	Training helped me to gain observation skills to note my child's behaviour and try to understand its causes.					
6	I have been able to observe my behaviour and its impact on my child.					
7	After training, I gain more confidence in my ability to help my child in the simplest way.					
8	I would recommend this training to other mothers.					
9	The coach used well prepared training material.					
10	Coach provided good information.					
11	Coach responded to audience's questions effectively.					
12	Coach was able to use good examples to clarify the information.					
13	Printed materials can be kept as references.					

**9. Training helped me to adopt the following ideas and attitude**

	<b>Statement</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>1</b>	Training my child is a legitimate humanitarian and as a parent I have the right to demand it.					
<b>2</b>	My goal is to help my child to his/her maximum ability and not to change him/her.					
<b>3</b>	My child is capable of learning according to his/her abilities and capacities.					
<b>4</b>	I am optimistic, yet realistic in my perception and expectation of my child's future.					
<b>5</b>	My child understands me and sympathises but lacks the ability to express his /her feelings.					
<b>6</b>	I understand that as a parent I sometimes put unrealistic expectations on the child that he/she is not responsible for. I understand that he or she is different in a way that he or she possesses certain capabilities that must be dealt with accordingly.					
<b>7</b>	I understand that it is possible to reduce the probability that my child might develop any future disorder or psychological damage resulting from failure to satisfy his/her mental, emotional, social and cognitive needs.					
<b>8</b>	I understand that family's role in enhancing child development is more important than specialist's role.					
<b>9</b>	It is my responsibility to demand child right.					
<b>10</b>	Everyday situations are an effective way to train my child if it's invested flexibly and creatively.					
<b>11</b>	I understand that by practicing, putting forth the effort and being flexible while teaching the basic skills, I am able to help my child.					
<b>12</b>	I understand that organizing my child's time and exposing him /her to a variety of activities is important to stimulate growth.					
<b>13</b>	I understand that by organizing my child's time and exposing him /her to a variety of activities helps in reducing hyperactivity and challenging behaviour.					
<b>14</b>	My child's current training increases his /her chances of having a functional future.					

**10. The following topics were important for me to discuss and clarify during the training:**

	<b>Statement</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>1</b>	Acquiring thinking skill.					
<b>2</b>	Discussing autism problem in the light of the Qur'an and Sunnah.					
<b>3</b>	Discussing the family role in claiming their rights					
<b>4</b>	Protecting the family from separation and loss					
<b>5</b>	Comparing the family's role to specialist's role.					
<b>6</b>	Defining autism, and identifying the different types of autism					
<b>7</b>	Knowing how to diagnose autism by the diagnostic criteria.					
<b>8</b>	Knowing the causes of autism and theories that explain it.					
<b>9</b>	Knowing the most effective types of intervention.					
<b>10</b>	Knowing conditions that should be considered in choosing the intervention.					
<b>11</b>	Identifying the traits of autism and comparing it to various stages of growth and brain function.					
<b>12</b>	Knowing the importance of sensory and motor input in stimulating brain growth function.					
<b>13</b>	Recognizing the importance of positive emotional experience and its role in stimulating brain function growth.					
<b>14</b>	Discussing my child's behaviour, sensory responses and skills in order to identify the child's strengths and weaknesses which are used to determine the functional performance level of the child.					
<b>15</b>	Learning how to identify and prioritize training objectives through observations collected on my child.					
<b>16</b>	Learning how to develop, evaluate and modify home-based intervention plan.					
<b>17</b>	Learning how to apply behavioural intervention and analysis overall objective to small training steps.					
<b>18</b>	Recognizing the importance of play as a training vehicle to stimulate brain growth and function.					
<b>19</b>	Knowing social story technique and how to use it as a mean of intervention approach to train child.					
<b>20</b>	Discussing some time management solutions and ideas for the mother.					
<b>21</b>	Discussing some time management solutions and ideas for the child.					

11. In my opinion, it is better to avoid discussions in the following topics with other trainees because it has nothing do to with the other trainees.

	Statement	Strongly agree	Agree	Do not know	Disagree	Strongly disagree
1	Acquiring thinking skill.					
2	Discussing autism problem in the light of Quran and Sunnah.					
3	Discussing the family role in claiming their rights					
4	Protecting the family from separation and loss					
5	Comparing the family's roles to specialist's role.					
6	Defining autism, and identifying the different types of autism					
7	Knowing how to diagnose autism by the diagnostic criteria.					
8	Knowing the causes of autism and theories that explain it.					
9	Knowing the most effective types of intervention.					
10	Knowing conditions that should be considered in choosing the components of intervention.					
11	Identifying the traits of autism and comparing it to various stages of growth and brain function.					
12	Knowing the importance of sensory and motor input in stimulating brain growth function.					
13	Recognizing the importance of positive emotional experience and its role in stimulating brain function growth.					
14	Discussing my child's behaviour, sensory responses and skills in order to identify the child's strengths and weaknesses which is used to determine functional performance level of the child					
15	Learning how to identify and prioritize training objectives through observations collected on my child.					
16	Learning how to develop, evaluate and modify home-based intervention plan.					
17	Learning how to apply behavioural intervention and analysis overall objective to small training steps.					
18	Recognizing the importance of play as a training vehicle to stimulate brain growth and function.					
19	Knowing social story technique and how to use it as a mean of intervention approach to train child.					
20	Discussing some time management solutions and ideas for the mother.					
21	Discussing some time management solutions and ideas for the child.					

**12. The following topics were not clear to me:**

	<b>Statement</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Do not know</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>1</b>	Acquiring thinking skill.					
<b>2</b>	Discussing autism problem in the light of Quran and Sunnah.					
<b>3</b>	Discussing the family role in claiming their rights					
<b>4</b>	Protecting the family from separation and loss					
<b>5</b>	Comparing the family's roles to specialist's role.					
<b>6</b>	Defining autism, and identifying the different types of autism					
<b>7</b>	Knowing how to diagnose autism by the diagnostic criteria.					
<b>8</b>	Knowing the causes of autism and theories that explain it.					
<b>9</b>	Knowing the most effective types of intervention.					
<b>10</b>	Knowing conditions that should be considered in choosing the components of intervention.					
<b>11</b>	Identifying the traits of autism and comparing it to various stages of growth and brain function.					
<b>12</b>	Knowing the importance of sensory and motor input in stimulating brain growth function.					
<b>13</b>	Recognizing the importance of positive emotional experience and its role in stimulating brain function growth.					
<b>14</b>	Discussing my child's behaviour, sensory responses and skills in order to identify the child's strengths and weaknesses which is used to determine functional performance level of the child					
<b>15</b>	Learning how to identify and prioritize training objectives through observations collected on my child.					
<b>16</b>	Learning how to develop, evaluate and modify home-based intervention plan.					
<b>17</b>	Learning how to apply behavioural intervention and analysis overall objective to small training steps.					
<b>18</b>	Recognizing the importance of play as a training vehicle to stimulate brain growth and function.					
<b>19</b>	Knowing social story technique and how to use it as a mean of intervention approach to train child.					
<b>20</b>	Discussing some time management solutions and ideas for the mother.					
<b>21</b>	Discussing some time management solutions and ideas for the child.					

13- Was the duration of the training period (six weeks, twice a week) enough?

If not, Why?

- Yes
- No

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14- Please write down any additional feedback you may have.

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## Appendix: G - Parenting Stress Index, Short Form

Name _____	Gender _____	Date of birth _____	Ethnic group _____	Marital status _____
Child's name _____	Child's gender _____	Child's date of birth _____	Today's date _____	

SA = Strongly Agree	A = Agree	NS = Not Sure	D = Disagree	SD = Strongly Disagree
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1. I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3. I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4. Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5. Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6. I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7. There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	SA	A	NS	D	SD
9. I feel alone and without friends.	SA	A	NS	D	SD
10. When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11. I am not as interested in people as I used to be.	SA	A	NS	D	SD
12. I don't enjoy things as I used to.	SA	A	NS	D	SD
13. My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14. Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
15. My child smiles at me much less than I expected.	SA	A	NS	D	SD
16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
17. When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
18. My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19. My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20. My child is not able to do as much as I expected.	SA	A	NS	D	SD
21. It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

22. I feel that I am:					
1. not very good at being a parent	1	2	3	4	5
2. a person who has some trouble being a parent					
3. an average parent					
4. a better than average parent					
5. a very good parent					

23. I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25. My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26. My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27. I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28. My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29. My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30. My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
31. My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

32. I have found that getting my child to do something or stop doing something is:					
1. much harder than I expected	1	2	3	4	5
2. somewhat harder than I expected					
3. about as hard as I expected					
4. somewhat easier than I expected					
5. much easier than I expected					

For the next statement, choose your response from the choices "10+" to "1-3."

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.	10+	8-9	6-7	4-5	1-3
34. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36. My child makes more demands on me than most children.	SA	A	NS	D	SD

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## Appendix: H - Sample Exercise and Story

Exercise I: Based on presented video determine the child stage of Functional Emotional Development?

Functional Emotional Development stages	Fully mastered	Partially mastered,	Not mastered
1. Regulation & Interest in the World.			
2. Engagement / Falling in Love			
3. Two-way Purposeful Communication			
4. Shared Social Problem Solving			
5. Creation of Ideas			
6. Logical Thinking			

Adapted from Greenspan 2010 the Basic Course test on the DIR/Floor-time Model (online version)

Exercise II: Use the following table to observe your child and to determine his/her Functional Emotional Development stage?

Functional Emotional Development stages	Fully mastered	Partially mastered,	Not mastered
1. Regulation & Interest in the World			
2. Engagement / Falling in Love			
3. Two-way Purposeful Communication			
4. Shared Social Problem Solving			
5. Creation of Ideas			
6. Logical Thinking			

Exercise III: Use the following steps to develop home- based intervention plan:

A. Create the child's growth profile by:

- Observe and understand the child's sensory response to environmental stimuli.
- Use the previous table to observe your child behaviour and to determine his/her Functional Emotional Development stage?

B. Use the collected information to:

- Determine and list the targeted skills based on previous observations:
- Priorities the targeted skills to be intervened
- Choose the intervention approach and implementation duration that fit each goal

Skill and goal	Intervention approach	Implementation Duration	Comment

C. Develop weekly, monthly schedules for each goal to assess the level of achievement and alter the intervention plan if needed.

First goal	Intervention approach	Implementation Duration	Start Date	Comment
<b>Step 1</b>				
<b>Step 2</b>				
<b>Step 3</b>				

Questions help in determining the child's level of functional emotional development <sup>41</sup>

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<sup>41</sup> Adapted from Greenspan (2010) the Basic Course on the DIR/Floor-time Model (online version)

1. Joint attention and interest in the world:

- Does your child look at you when you talk to him/her?
- Does your child share smiles and smile back to you when you smile to him or her?
- Does the child answer when you call his/her name?
- Does the child able to transfer his attention from one activity to another activity with the ability to return to the previous activity?

2. Engagement / enjoyment and Falling in Love:

- Does the child feel the presence of others around him?
- Can the child attract the attention of others?
- Does the child interact with his/her parents and siblings?
- Does the child initiate any social interaction?
- Does the child enjoy friendships with children who are in similar age?

3. Two-way Purposeful Communication

- Does the child communicate visually with others for reasonable period of time?
- Does the child express feelings of joy and happiness when you talk or play with him/her?
- Does the child insist to attract your attention and talk to you even if you are busy?
- Does the child sympathy you if you cry or pretending to do so?

#### 4. Shared Social Problem Solving

- Does the child share turn taking with others?
- Does the child trying to test your reaction to new situations?
- Does the child try to solve the problems he /she might confront (such as game play audio or open a juice carton)?
- Does the child use body language (gestures, facial expressions) to express himself/herself?

#### 5. Creation of Ideas

- Does the child use the language to express his needs and feelings?
- Does the child use the language in his/ her play?
- Does the child tell you about things happened to him/her when you're not with him?
- Does the child play properly?
- Does the child imitate in his/ her play some activities (such as prayer, cooking, reading the newspaper, studying...etc).

#### 6. Logical Thinking

- Does the child able to relate current situation with old one?
- Does the child able to compare things (two cars in terms of differences or similarities)?
- Does the child able to tell you story from his/her imagination?
- Does the child able to tell you different reasons behind his/her refusal or acceptance to get things?
- Does the child plan to go to places such as shopping or visiting relatives?
- Does the child use simple mathematical concepts? For example, I have two sisters?

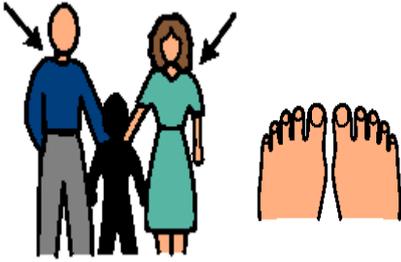
# الارجل Feet



انا أحمد  
I am Ahamad



انا عندي رجلين صغيرة  
I have two little feet

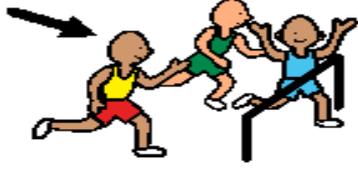


ماما و بابا عندهم رجلين كبيرة  
Mum and dad have big  
feet



الزوار عندهم رجلين  
Visitors also have feet

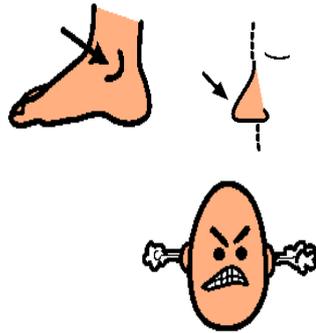




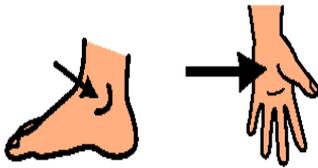
الأرجل نمشي ونلعب بها  
we walk and play with  
feet



إذا لمست رجل احد يزعل  
Touching others' feet  
upsetting them



إذا شميت رجل احد يزعل  
Smelling other's feet  
upsetting them



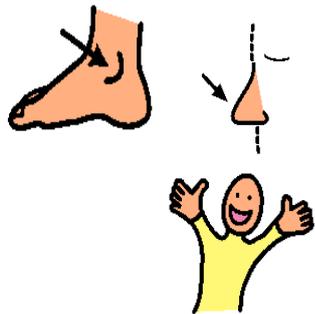
أنا شاطر ما ألمس رجل احد

I am good I do not touch  
other's feet



أنا شاطر ما أشم رجل احد

I am good I do not smell  
other's feet



## Appendix: I - List of References of Information and Videos

- **Early intervention programmes**  
<http://www.childguidanceclinic.com/Autism%20book%204.htm>  
<http://www.werathah.com/special/inter/portage.htm>
- **General information on available intervention approaches for autism**  
[http://www.shafallahautism.org/arabic/ser\\_best.html](http://www.shafallahautism.org/arabic/ser_best.html)  
<http://autism.healingthresholds.com/therapy/applied-behavior-analysis-aba>  
<http://www.alami.ae/122.html>
- **Visual Aids**  
[http://www.autismhandinhand.com/program\\_materials.htm](http://www.autismhandinhand.com/program_materials.htm)
- **Toilet training**  
<http://www.youtube.com/watch?v=xA8wmqPI63M&feature=related>
- **Article about the importance of play and its relationship to autism**  
<http://kayanegypt.com/forum/t1629.html>
- **Board-maker website.**  
<https://www.boardmakershare.com/>
- **Videos are employed in the training to clarify the learning process and the developmental stages in children.**
  - <http://www.youtube.com/watch?v=obtS5HP4li4&NR=1>
  - <http://www.youtube.com/watch?v=ONtf9mteehE&NR=1&feature=fwp>
  - <http://www.youtube.com/watch?v=ONtf9mteehE&NR=1&feature=fwp>

Learning

Developmental stages

## **Appendix: J - A Brief Description of Autism and Autism Services Booklet**

The aim of this booklet is to provide parents with basic and easy to access information at post-diagnosis stage as this stage associated with many difficulties.

Therefore, the booklet is covering the following topics:

- ✓ Autism spectrum disorders definition.
- ✓ Autism diagnostic criteria.
- ✓ Autism spectrum disorders sub- types.
- ✓ Disorders may coincide with Autism.
- ✓ Autism and medical tests.
- ✓ Causes of autism.
- ✓ Treatment of autism.
- ✓ Current provided services.

Thus, translating the whole booklet from Arabic to English proved to be difficult do to study time limitation. Therefore, the Arabic version was provided to give the reader with an idea about this booklet.