AN EDUCATION PROGRAM FOR MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN JORDAN

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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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Abstract

The present study aims to understand the experience of parenting a child with ASD in Jordan and to determine whether the provision of an education program in Jordan for mothers of children with ASD increased mothers’ understanding of their child’s behaviour and improved the mothers’ coping skills and reduced their stress levels. The difference between mothers’ and fathers’ coping skills and stress was also examined. In addition, this study explored the fathers’ and professionals’ views of how disability is regarded in Jordanian culture.

A mixed methods study was conducted to satisfy the research aims. The qualitative aspect involved a series of interviews and focus groups. The interviews were held with 10 mothers of children with ASD and two focus groups with 10 fathers and 10 professionals. The quantitative data involved a pre- and post-intervention questionnaire comprised of two scales assessing coping skills and stress. Pre-intervention interviews and a pre-intervention questionnaire were administered before commencing the implementation of the parent education program to identify the mothers’ needs, to understand their experiences, and to discuss how Jordanian culture understands disability. Post-intervention interviews and a post-intervention questionnaire were carried out at the conclusion of the education program with the mothers to evaluate the effects of the program. Fathers’ and professionals’ focus groups were conducted to discuss how Jordanian culture understands disability. The same questionnaire that was given to the mothers was also administered with the 10 fathers and was comprised of two scales assessing coping skills and stress.

The results showed that following the education program the mothers reported a statistically significant reduction in stress levels, an increase in coping skills, and an improvement in mother–child interaction. Furthermore, the findings showed that from the perspective of the fathers and professionals, Jordanian society did not readily accept people with a disability in general and that there were few provisions to support families with a child with ASD. The research described in this study has valuable implications for practice and intervention for families with a child with ASD living in Jordan.
Chapter 1: Introduction

This chapter provides an introduction to the thesis which has two main aims. The first aim is to understand the experience of parenting a child with Autism Spectrum Disorder (ASD) in Jordan. The second aim is to determine whether the provision of an education program in Jordan for mothers of children with ASD, increased mothers’ understanding of their child’s behaviour and improved the mothers’ coping skills and reduced their stress levels. Parenting a child with ASD is particularly stressful because children with ASD often exhibit challenging behaviours that interfere with the child’s ability to learn and that disrupt everyday family life.

This chapter introduces the definition and characteristics of Autism Spectrum Disorder (ASD) and explains its causes, diagnosis and problems, before identifying the main goals of the research, the significance of the research, and the research questions. The chapter provides a description of the child and parent support approaches, including parent support in Jordan. It also presents a brief discussion of the conceptual model of the present research, the research methodology, research site and definitions of the key concepts used in the present study. The final section of this chapter describes the organisation of the thesis.

1.1 Autism Spectrum Disorder: Definition and characteristics

Autism Spectrum Disorder is the expression used to describe a group of disorders that includes autism, Asperger syndrome as well as pervasive developmental disorder (also referred to as atypical autism). Autism is the most common form of ASD (Duncan, Holverstott, Myles, & Swanson, 2007). The word spectrum can be used since the range as well as severity of the problems that individuals with ASD encounter may differ extensively. Sometimes the word autism is employed to refer to all the disorders which include ASD. However, for the rest of this work, the term ASD is consistently used in reference to all of the autism disorders.

ASD is a lifelong developmental disability that is defined by specific criteria. These criteria characterise marked problems in social interaction, social communication, repetitive behaviour as well as restricted interests (Autism Research Institute, 2007; Smith, Myles, Swanson, Holverstott, & Duncan, 2007).

For many years ASD was regarded as rare, with just 5 children per 10,000 diagnosed with this condition (American Psychiatric Association, 2000). However, since the 1990s the
Diagnosis of ASD has grown exponentially with figures reported as high as 60 for every 10,000 (Fombonne, 2003). Typically, the percentage of diagnosis is one girl to four boys (Williams, MacDermott, Ridley, Glasson, & Wray, 2008). The Centre for Disease Control reported that the incidence of children with ASD in the USA in 2007 was one in 150 children (Autism Research Institute, 2007). In a recent Australian ASD prevalence study, the incidence of children on the autism spectrum in Australia was high as one in 160 children (Australian Psychological Society, 2010).

1.2 Autism Spectrum Disorder: Causes and diagnosis

Presently, there is no known cause for ASD. Researchers believe that the environment and genes are factors related to ASD; others assume there may be different causes (Smith, et al., 2007). “ASD is a disorder of the nervous system and of the immune system that affects multiple metabolic pathways” (Megson, 2000, p. 1). Megson also stated that “Autism may be a disorder linked to the disruption of the G-alpha protein, affecting retinoid receptors in the brain” (p. 4), and that many individuals with ASD appeared to have highly abnormal lipid profiles.

ASD is diagnosed through an evaluation which combines observing and questioning the children, their family and service providers. Data is accumulated noticing the children’s strengths and problems, especially in the regions of social communication, social interaction, repetitive behaviour or restricted interests. Such data could be acquired from standardised tests or surveys. Symptoms commonly begin before age three and can cause problems or delays in numerous skills. ASD is more often than not promptly diagnosed in later childhood and adolescence (Zager, 2005). There is no single behaviour or medical test that can identify ASD. Specialists and clinicians with experience and background in assessing people with ASD are qualified to diagnose individuals with ASD (Smith, et al., 2007).

Parents are usually the first to recognise developmental differences in their children. Such differences are usually associated with difficulties such as failure to develop speech, and challenges to interact with the parents and others. Parents commonly sense that there is something wrong with their child, for instance, that their child is not reacting to them as he/she should (Hollander, 2003; Zager, 2005).
1.3 Autism Spectrum Disorder: Characteristics

Children and adults with ASD typically have some degree of functional deficit or problems across three main areas including communication, social interaction and repetitive behaviour or restricted interests.

1.3.1 Communication

Children with ASD typically have problems in understanding and using verbal and non-verbal communication. Communication difficulties are often the first concern parents have about their child’s development and lead them to look for professional aid (Hollander, 2003; Smith, et al., 2007; Zager, 2005).

Children with ASD usually have speech problems and many of them do not utilize speech to show what they need. Alternately, they could utilize various frames of early communication, for instance, utilizing their parent’s hand as an apparatus to get something they need. Most obviously children with ASD additionally have a problem understanding what is stated to them, even if their hearing ability is unimpaired (Hollander, 2003; Smith, et al., 2007).

1.3.2 Social Interaction

Social interaction is another difficulty for children with ASD. An example of the challenges that children can experience is restricted use as well as understanding of non-verbal communication such as facial expressions, tone of voice or eye contact (Bromley, Hare, Davison, & Emerson, 2004). Because of their limited ability to understand other individual's emotions, they often do not develop friendships easily (Autism Research Institute, 2007; Smith, et al., 2007). Children with ASD frequently don’t express their own enjoyment or interest in others. Other social problems may include little no understanding of other individual's emotions, and also trouble playing with peers. Children with ASD may seem bored with others or attempt to communicate with others in unusual ways (Hollander, 2003; Smith, et al., 2007).

1.3.3 Repetitive Behaviour and Restricted Interests

Children with ASD often illustrate unusually intensive or concentrated passions in particular items or actions. Such children may be intensely enthusiastic about specific things, topics or perhaps activities such as puzzles, insects, trains, dinosaurs, characters as well as numbers or certain TV shows (Gense & Jay, 2005). Additionally, they often display
unconventional or even repeated actions. For example, they may spin their bodies, flutter their hands and arms or use other atypical physical actions. Many children with ASD depend on routines and rituals, and can insist that activities such as driving towards the shops or bath time be completed exactly the same way each time (Frea & Hepburn, 1999). Children with ASD often show intense fascination with elements of objects, for example, a desire for playing with the wheels of a toy car or playing with a toy’s on/off switch rather than playing with the toy itself (Hollander, 2003; Smith, et al., 2007).

1.4 Child Support Approaches

At present, no treatment solution totally ameliorates the characteristics of ASD. However, numerous techniques have proved effective with some children in research settings. The best-researched programs derive from applied behaviour analysis, and treatment programs based on behavioural principles are widely used for children with ASD (National Research Council, 2001a).

These programs are highly structured and can be performed in one-on-one therapy sessions through to naturalistic settings using typically developing children as models. Early forms of behavioural programs were very organised, intensive, structured, one-on-one plans, that proved to be highly effective with as many as half of the children involved (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). These types of structured programs are expensive and children frequently had difficulty generalizing the programs’ outcomes into other settings. To address this matter, researchers began using less structured, more realistic, behavioural programming in the school and other sites (e.g., Schreibman & Koegel, 1996).

Studies based on inclusion models (i.e., educating children with ASD along with their peers without a disability) and using naturalistic behavioural methods show good success for children with ASD (National Research Council, 2001b; Zager, 2005). Much like research regarding in-home programs, inclusion programs result in as many as 50 percent of children being integrated into typical education programs (Handleman & Harris, 2008).

Some strategies entail comprehensive educational programs, while others give attention to a specific area, for example behaviour or communication problems. Some techniques that are not behaviourally natural are beginning to show results as well. Some of these are practical techniques which coordinate the surrounding environment of children with ASD. The goal of these programs is to help children with ASD better understand the environment surrounding them and operate inside it more independently. Such programs are independently...
developed around every individual's advantages, abilities, interests and requirements. The structured training makes use of visual cues to aid youngsters with ASD as they move throughout their particular surroundings (Gense & Jay, 2005). Parent Support Approaches

Parents of children with ASD play a crucial role in assisting their own child’s learning, and in developing skills in behavioural and educational programs. In many programs, parents do not only make decisions about their children, they play a primary part in the actual intervention (Baird & Peterson, 1997; Turnbull & Turnbull, 1986).

Parent education programs are an example of parent support approaches. Education programs for parents of children with ASD have become an effective way for training family members in successful behavioural strategies to manage their child’s behaviour (Gross, Fogg, & Tucker, 1995). Many parents of children with ASD have stated that it is hard to know which treatment or intervention options to choose and that it would be useful to have up to date information regarding available treatment options and support services for children with ASD (Pratt, 1998).

A parent education program is the process associated with providing parents’ information and support from major care providers having particular knowledge and also childrearing expertise. The dual objectives associated with such programs are promoting the parent’s skills and promoting the development of the children. This emphasis is mirrored in family-centered methods, (discussed in a later section) and early intervention (Binnendyk & Lucyshyn, 2009; Duwa, Wells, & Lalinde, 1993). Even though just about any action which parents get embroiled in within early intervention could be interpreted as educational, the term parent education typically refers to organized routines delivered through professionals to aid parents in accomplishing certain objectives with their children. An aim of parent education includes the expectation that parents may obtain the understanding and skills that permit them to mediate and lengthen their interaction with their child. Common targets of parent education consist of teaching parents appropriate ways to support children throughout attaining developing abilities, supporting parents to control their own child’s behaviour in the course of everyday activities, and improving parents’ abilities to participate in their child’s life and social interactions (Moes, 1995; Roberts, Wasik, Casto, & Ramey, 1991; Whiaker, 2002). Consequently, many parents require education in order to comprehend their child’s diagnosis and also to help them to create knowledgeable choices regarding service choice that is available (Birkin, Anderson, Seymour, & Moore, 2008).
1.5 Parent Support in Jordan

In Jordan, there are few special education centres offering information, resources and services for children with special needs. There are six main special education centres in Jordan that serve a very small percentage of children with ASD. The main centres providing services for children with ASD are the Specialty Institute for Special Education, the Jordan Specialized Centre for Autism, the Jordanian Association for Behaviour Analysis, the Consultative Centre for Autism, the Communication Centre for Autism and the Jordan Academy for Autism. Most of these centres provide services to about 20 students who are between 3-19 years of age, with a trainer:child ratio of 1:5. In these centres, children are supplied with academic, daily life activities, and imaginative works for example drawing and music as well as sports and physical education, but typically, parent education programs are not provided. The services have been primarily directed to the children without paying much attention to the needs of their families.

In many counties, parent education programs have been used to provide parents with effective methods for instructing their children and also to improve the child’s functioning in the home environment (Birkin, et al., 2008; Roberts, et al., 1991; Shields, 2001; Sussman, 1999). These programs are also used to improve parent’s coping skills and to reduce the challenges related to parenting a child with ASD, for example stress (Davis & Carter, 2008). The outcomes of these education programs have the possibility to produce substantial long-lasting changes in conduct causing enhanced standard of living for the children and their family (Ozonoff, Dawson, & McPartland, 2002; Sussman, 1999). However, in Jordan there are still no such education programs for parents of a child with ASD (Asaod, 2008; Autism Academy of Jordan, 2007). Therefore, the present study aimed to explore whether the provision of an education program in Jordan for mothers of children with ASD, improved the mothers’ coping skills, reduced their stress levels and enhanced their understanding about their child’s behaviour.

1.6 Statement of the Problem

In Jordan, there are few special education centres offering information, resources and treatment for children with ASD. All these centres are located in the capital city of Amman. For families living far away from Amman, sending their children to these centres for treatment is costly and time consuming. Even for those families with access to these centres, fee for service charges at the centres limit their availability to families. Therefore, the
importance of this study is to help Jordanian parents of children with ASD to improve their knowledge about their child’s behaviour, to increase the parent’s coping skills and to reduce the parent’s stress by using a parent education program. Such programs can be implemented locally without the need for families to travel long distances and to incur substantial costs.

Another problem in relation to families of children with ASD in Jordan concerns the few studies that have been conducted to date on this important issue. The extant research almost exclusively deals with children with ASD, but does not provide any implications that have direct relevance to the parents of children with ASD (Asaod, 2008). To the researcher’s best knowledge, there has not been a single study conducted in Jordan to assess the effectiveness of education programs for parents of children with ASD. It is therefore essential to pursue this topic.

A third problem is that none of the previous studies in Jordan have attempted to investigate differences between mothers’ and fathers’ coping skills and stress. The present study also examined if there were differences between Jordanian mothers’ and fathers’ coping skills and stress levels.

1.7 The Specific Research Questions

The present study aimed to examine the effects of an education program in Jordan for mothers of pre-school age children with ASD. The difference between mothers’ and fathers’ coping skills and stress was also examined. In addition, this study explored fathers’ and professionals’ views of how disability is regarded in Jordanian culture.

The specific research questions were:

1. How do Jordanian mothers experience parenting a child with ASD?
2. Are there differences between mothers’ and fathers’ coping skills and stress levels in families with a young child with ASD?
3. What effects does a training program have on the coping skills and stress levels of mothers of children with ASD?
4. How is disability regarded in Jordanian culture by parents and professionals?

1.8 Research Conceptual Model

The present study uses three elements of Bronfenbrenner’s (1979) ecological system to build a conceptual model. These elements are the microsystem, mesosystem and
macrosystem. A fuller discussion of this model and its relevance to the present research is provided in chapters 2 and 3. Briefly, however, Bronfenbrenner’s theory describes the complex bi-directional social influences surrounding a child as a set of concentric circles nesting within each other and with the child at the centre. The microsystem is the inner-most circle and consists of a few main persons; the parent(s) and a child. The mesosystem element consists of the child’s interactions in environments outside the family home, such as child-care settings, professionals’ or school, and also includes the immediate supports available to families, such as extended family members, friends and the workplace and neighbourhood. The family is the most influential part of the mesosystem because the influence of the family extends to all aspects of the child’s development, particularly during the early years of life when children are dependent on their immediate care-givers, to provide for their cognitive and social development, nutrition, security and health (Moore, 2006). A major focus of the present study was the inclusion of an education program for Jordanian mothers to help them improve their knowledge about their child with ASD and to increase their coping skills and reduce their stress level. According to Bronfenbrenner’s (1979) model, improvements in family functioning will have a flow-on effect to children’s progress and well-being. The effects of the macrosystem, the outer-most circle in Bronfenbrenner’s model were also investigated because the macrosystem contains the broader socio-cultural factors, such as the general beliefs and values of the surrounding culture, that will influence family functioning. In this study, the macrosystemic aspect was investigated via professionals’ and fathers’ views towards disability in the Jordanian culture.

1.9 Research Methodology

This section presents the methodologies utilized in the data collection and analysis for this research, with full details provided in chapters 3 and 4. A mixed methods study was conducted to satisfy the research aims. The qualitative aspects involved a series of interviews and focus groups. The interviews were held with 10 mothers of children with ASD. The interviews sought to identify the mothers’ needs, to understand their experiences, and to discuss how Jordanian culture understands disability. Two focus groups were conducted with 10 fathers (husbands of the mothers) and two separate focus groups were conducted with 10 professionals. Fathers and professionals focus groups were conducted to discuss how Jordanian culture understands disability. Quantitative data were obtained from the mothers and fathers by a questionnaire comprised of two scales assessing coping skills and stress. The questionnaire was administered to the mothers before commencing the implementation of the
parent education program and the same scales were re-administered at the conclusion of the education program to evaluate the effects of the program. The same questionnaire was also administered to the 10 fathers before the focus group discussion commenced.

1.10 Research Site: Jordan

“The Hashemite Kingdom of Jordan (Jordan) is approximately 60,000 square miles and is located in the heart of the Middle East. It is northwest of Saudi Arabia, south of Syria, southwest of Iraq and east of the West Bank. Jordan also has access to the Red Sea via the port city of Aqaba, located at the northern end of the Gulf of Aqaba” (Kubow, Darabie, Collet, & Frey, 2009, p. 2). The population of Jordan was estimated in 2011 at 6.25 million (Department of Statistics, 2011).

Jordan is an independent Arab nation and the official language is Arabic, and the official religious belief is Islam. Amman is the capital city of Jordan, and the Jordanian people are part of the Arab nation. The education system in Jordan has received considerable attention since the Kingdom’s establishment in 1921 via King Abdullah I’s efforts to accomplish national unity. Jordan won its full independence on May 25, 1946, following the end of the British mandate (Salibi, 1998).

Jordan’s literacy rate of 91.3% is high compared to other countries in the region. The Jordan Ministry of Education has rolled out advanced nationwide programs. Jordan’s academic program reflects worldwide standards and its education program is recognized in world-class universities (Kubow, et al., 2009).

1.11 Definition of Key Parent Outcomes

Parenting stress: Stress is caused by recognized differences between private resources and situational needs (Lazarus, 1984). Based on this view, the bigger the disparity involving the perceived situational demands and private resources, the more stressed a person can feel. Therefore, parenting stress is a result of differences between expectations parents have for themselves and their child, compared to what is actually experienced (McBride, 1989). Parenting a child with ASD is particularly stressful because children with ASD often display challenging behaviours which restrict the ability of the child to understand the world around them and that affects family life. Many studies have concluded that parents of children with ASD are likely to experience more stress than parents of children with other developmental

**Coping style:** Coping style is a concept used to describe the personal aspects associated with managing personal demands (Heszen-Niejodek, 1997). Coping style is viewed as an individual dispositional variable which is usually comparatively stable. Anxiety is a common problem experienced by parents attempting to cope with life after diagnosis of their child’s disability (Altiere & Kluge, 2009; Heszen-Niejodek, 1997; Lazarus, 1984; Tunali & Power, 2002). Daniels (1999) indicated three main forms of coping strategies including emotion-focused, problem-focused and perception-focused coping. Emotion-focused coping tries to reduce the emotional distress associated with a specific situation while problem-focused coping tries to reduce the stress simply by modifying the situation. Perception-focused coping tries to change the individuals’ evaluation of the situation. The use of positive coping strategies has been cited as a method to reduce stress in parents of a child with a disability (Ergüner-Tekinalp & Akkök, 2004; Sirbasku-Cohen, 2001).

1.12 Organisation of the Thesis

This thesis contains five chapters. Chapter one presents the background rationale, purpose, definition of terms, and the significance of the present study. Chapter two reviews the literature related to the two major content areas for this study (parenting stress and coping), and their relationship to education programs for parents of children with ASD. Chapter two also introduces the theoretical approaches that are used to build a conceptual model for the present study.

Chapter three introduces the overview of the research methodology employed in the current study. Chapter four presents a description and discussion of the qualitative and quantitative analyses that were conducted on the sets of data collected for the purposes of the current project. Chapter five includes a discussion of the results of this study, limitations of the current study, recommendations for the application of the research results, and recommendations for future research and concluding remarks.
Chapter 2: Review of the Literature

2.1 Overview

The primary aim of this study centres on the outcomes associated with the provision of an education program for mothers of children with ASD in Jordan. The first part of this chapter describes the historical background to the provision of services for young children with a disability and their families in developed countries and provides the theoretical framework for the study. The next section reviews the existing literature concerning education and support programs for parents of children with ASD. This section investigates what is known about existing education and support programs and identifies any knowledge gaps or problems with these programs. This is followed by a discussion of the outcomes of parent education and support programs and the final part of the chapter addresses cultural norms about disability in Jordan.

2.2 Theoretical Framework

This section introduces the theoretical approaches that were used to build a conceptual model for the present study. Two theoretical approaches related to early intervention are relevant for the present study. First, a summary of the evolution of early intervention services for children with disabilities will be introduced, followed by a discussion about each of the explanatory theories. The first theory described is Bronfenbrenner’s (1979) ecological systems theory, which acknowledges the importance of including families in any intervention designed to support young children, as well as the effects of the broader social structure on family functioning and child development. The second theory discussed is the family-centered approach to early intervention which aims to support families and build their capacity to provide optimal care for their young child with a disability.

2.2.1 Early Intervention

Early intervention (EI) for children with disabilities started in the 1960s with a child focused approach (Birkin, et al., 2008). Child-focused services primarily took the form of professional interventionists, for instance occupational therapists, speech pathologists and special educators, working directly with the child typically in one-to-one activities (Moore, 2006). More recently, knowing the role the family takes in the integration and carryover of care, the main focus changed from child-centered to family-centered service (Turnbull & Turnbull, 1986). The philosophy of family-centered care promotes the management of the
child within the framework of the family in order to be able to optimize the particular child’s
development. The move from an exclusive child-focused function of service to one which
also includes services directed at parents and the family as a whole represents the adoption of
an ecological systems perspective that has had profound ramifications for early intervention,
broadening the aims and the range of services (Baird & Peterson, 1997).

2.2.2 Ecological Systems Theory

Bronfenbrenner (1979) developed a theory of an ecological system which explains
human development and the influence of the surrounding environment (ecology) on human
behaviour. He claimed that human behaviour is a complex system which is influenced by a
number of factors. The ecological framework consists of four layers which are the
microsystem, mesosystem, exosystem and macrosystem.

The microsystem is the layer nearest for the child and contains the structures with
which the child has immediate contact. Structures in the microsystem encompass the social
and physical environment of the family and include the interactions as well as experiences a
child has within their immediate family environment (Berk, 2000). At this stage, the
relationship is in two directions - both from the child and also towards the child. As an
example, a child’s parents may affect the child’s beliefs and behaviour; however, the child
additionally affects the parents’ behaviour as well as their beliefs. Bronfenbrenner called
these bi-directional influences, and he confirmed that they happen among all layers of the
environment. The interaction of structures inside a layer as well as interaction of structures
between layers is a principle to this theory.

The mesosystem includes the interrelationships between the major settings in which the
child functions, such as the extended family and the child’s school or early childhood centre.
At the mesosystem level, bi-directional effects are most powerful and have the greatest
influence on the child. Nonetheless, interactions from outside layers can still affect the inner
constructions. These bi-directional relationships are indicated in Figure 2.1.

The exosystem identifies the bigger social system where the child does not function
immediately. The structures in this layer impact the child’s development by interacting with
their microsystem (Berk, 2000). Parent employment status, neighbourhood support, social
policies and community-based family resources are examples. Although the child is not
directly involved, because of the influences of these factors on family functioning, the child
may feel positive or negative forces associated with the exosystem.
The macrosystem is the outermost layer in the child’s environment. This layer is composed of cultural values, customs, and laws (Berk, 2000). The consequences of such principles have a cascading impact through all the different layers. For example, if the culture assumes that mothers and fathers are entirely responsible for raising their children, that culture will not be as likely to supply resources to assist parents. Consequently, the parents’ capacity or inability to meet this responsibility for their child affects the child’s microsystem.

The conceptual model for this study, presented in Chapter 3, focuses on three elements ofBronfenbrenner’s ecological systems theory in the Jordanian context, these are the microsystem, mesosystem and macrosystem.

![Bronfenbrenner's ecological systems theory](image)

**Figure 2.1: Bronfenbrenner's ecological systems theory**

### 2.2.3 Family-Centered Approaches

The history of family-centered approaches stems from the 1980s when there was a move away from early intervention professionals providing direct services to assist children with disabilities to a focus on supporting the families of children with disabilities (Binnendyk
Assisting parents and the family are now acknowledged as crucial goals of Early Intervention in conjunction with assisting the child.

In addition to the structured educational and therapy services offered directly to children, a range of programs for parents were introduced including counselling support, parent-to-parent programs and education programs (Handleman & Harris, 2008). Programs for other family members were also introduced including programs for grandparents, siblings, childcare providers, financial counselling and support. Bronfenbrenner’s ecological model highlights the important role of the family in the care and education of a child and also the significance of assisting parents to mobilise nearby supports through standard methods, instead of entirely relying on specialist services (Berk, 2000).

Family-centered service is now considered to be “best practice” in many areas focused on the development of children, including early intervention (Baird & Peterson, 1997) and paediatric rehabilitation (King, et al., 2003). Family-centered support is a philosophical approach to support the children and their families (Baird & Peterson, 1997; Binnendyk & Lucyshyn, 2009). This support approach creates partnerships between service providers and families, and provides families with the information they need to make informed decisions and to provide supportive care (Dempsey & Keen, 2008; King, et al., 2003). As a result, service providers must have the necessary capacity to efficiently communicate with parents and also to identify and appreciate their diverse situations when designing interventions (Birkin, Anderson, Moore, & Seymour, 2004; Iversen, Shimmel, Ciacera, & Prabhakar, 2003).

The foundations for family-centered practices are the values and beliefs about how professional help givers must connect with family members (Binnendyk & Lucyshyn, 2009). The family-centered approach has become the practice-of-choice in many programs such as early childhood intervention programs (Duwa, et al., 1993) and parent education programs (Roberts, et al., 1991). Johnson, Jeppson and Redburn (1992, p. 3) state that the main features of family-centered care are:

1. Recognizing the family as central to and/or the constant in the child’s life, and the child’s primary source of strength and support;
2. Acknowledging the uniqueness and diversity of children and families;
3. Acknowledging that parents bring expertise to both the individual caregiving level and the systems level;
4. Recognizing that family-centered care is competency enhancing rather than weakness focused;

5. Encouraging the development of true collaborative relations between families and health-care providers, and partnership; and

6. Facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families.

The following section examines a range of family-centred programs designed to support parents of children with Autism Spectrum Disorder.

2.3 Parent Education and Support Programs

Children with ASD often signify a challenge to their families (Birkin, et al., 2004; Hassall & Rose, 2005). The functional deficits of children with ASD may lead to high anxiety in parents. As mentioned previously, highly structured programs for children with ASD were extremely expensive and children often had difficulty generalizing the information they learned in one-to-one therapy or education sessions into everyday life and other settings. Consequently, researchers began using less structured and more naturalistic programs (Roberts, et al., 1991; Schreibman & Koegel, 1996). In the past 20 years, a wide range of therapies have attempted to reduce anxiety and stress in parents through the use of parent education programs (Birkin, et al., 2008). Parent training programs were developed to offer parents an effective means of instructing their children and to increase the child’s functioning in the home environment. Parent training programs typically included strategies to help the children interact with and communicate with their family and become a more active participant in school and family life (Ozonoff, et al., 2002). These programs also helped reduce the challenges associated with parenting a child with ASD, like the concern associated with stress (Davis & Carter, 2008).

Today, education and training programs are considered one of the most important supports for parents of children with ASD (Papageorgiou & Kalyva, 2010). Researchers have focused primarily on parent education programs in the belief that it would be helpful to supply parents with information about numerous educational methods, about available treatment options and about support services for their children with ASD (Birkin, et al., 2004).
2.3.1 EarlyBird Program

The EarlyBird program was produced by the National Autistic Society of the United Kingdom and targets families of children aged between two and four years, soon after their diagnosis of ASD (Shields, 2001). The EarlyBird program provides families with education about how to develop better social communication and interactions with their child (Birkin, et al., 2004). The program aims to help parents create knowledgeable decisions and options regarding their children, thus reducing parental stress and reducing reliance on experts (Birkin, et al., 2008). The EarlyBird program is delivered over 12 weeks, which includes eight 3-hour daytime teaching classes, and four home visits by an EarlyBird trainer. Video-recordings of parent-child play interactions made during the home visits are usually examined throughout the teaching sessions.

The EarlyBird program has been offered in several parts of the UK since its introduction in 1997, and has also been adopted in other countries including Ireland, Israel, New Zealand and Malta (Birkin, et al., 2004). In the UK, the EarlyBird program was evaluated using 30 families. The results of the evaluation indicated the program's efficacy in reducing parental stress and improving adaptive functioning in children with ASD (Hardy, 1999). Birkin et al. (2004) also reviewed the effectiveness of the EarlyBird program and indicated that the program showed best practice in early intervention in comparison to other techniques. The effectiveness of the EarlyBird program was assessed using subsequent parent reported positive outcomes including: 1) effective ways to manage challenging behaviour; 2) increased information about ASD; 3) development of play and daily living routines; and 4) improved language interactions.

2.3.2 The Hanen Program/More than Words

The Hanen program was developed by the Hanen Centre (Sussman, 1999). The Hanen Centre is a government-funded organization in Toronto, Canada, which specialises in education health care providers to help communication development in children from birth to six years. More Than Words is an intensive training program from Hanen for parents of preschool children with ASD (Sussman, 1999). This program provides parents with helpful equipment, including guidebooks and DVDs, to use with their children to help them communicate. The aim of the program is for parents to learn using their child’s daily routines as the framework for learning how to communicate. The program is designed to help parents with children with ASD under six years of age who have difficulty with language and social interactions. The program applies the principles of adult learning to educate several parents in
eight interactive classes for parents and three individual in-home video recording and coaching sessions for parents and their child. The initial video recording session is a component of the pre-program examination. Sessions are held weekly with the exception of the weeks of the home video recording sessions. By means of practical hands-on education the aim of this program is to enable parents to turn everyday activities into learning experiences (e.g. what kind of language to use with the child, what motivates them to communicate) (Sussman, 1999).

An evaluation study was conducted by McConachie, Randle, Hammal, and Le Couteur (2005) for 51 children with ASD between the ages of two and four years who received the More than Words Hanen training program. One group received intervention immediately, and the other group obtained the intervention following a delay. Results were measured seven months after recruitment. These included measures of parents’ use of facilitative methods (e.g. use of entertaining phrases, simplified vocabulary, musicality associated with speech, accepting physical contact), parent stress levels, as well as the parents’ ability to adapt activities to meet their child’s needs. Measures were additionally obtained of every child's development in regard to the size of their vocabulary, behaviour difficulties, as well as social-communication abilities. The results indicated that the children of parents who commenced the course immediately had a larger vocabulary compared to the children whose parents were delayed in attending the program. However, these findings should be considered in light of the fact that just a small number of children were involved in the study, allocation to groups had not been randomized, the follow up period was short (7 months) as a result of the second group needing to begin the program, and also the postponed group had been getting other interventions while waiting for the program (McConachie, et al., 2005).

2.3.3 Family-Centred Positive Behaviour Support (PBS) Programs

Positive Behaviour Support (PBS) focuses on using positive reinforcement to encourage and increase children’s appropriate behaviour and has been used in schools to develop support systems for effective school-wide practices for children with ASD (Binnendyk & Lucyshyn, 2009). A number of studies have demonstrated the efficacy of merging family-centred intervention with PBS (Lucyshyn, Dunlap, & Albin, 2002; Marshall & Mirenda, 2002).

Family-centred PBS programs involve a collaborative relationship between families and professionals with consideration of families’ requirements to address their child's challenging behaviour (Everett, 2001; Sirbasku-Cohen, 2001). Family-centred PBS is often
carried out within the environment of natural routines that happen frequently in home or society settings and typically involve five phases for supporting the everyday activities for children with ASD in school age (Boettcher, Koegel, McNemey, & Koegel, 2003; Marshall & Mirenda, 2002). The five phases are: 1) Constructing relationships between the family and the professionals; 2) Conducting a practical assessment of the behaviours of the habits or concerns; 3) Identifying natural routines as contexts for intervention; 4) Building conduct support plans associated with each of the routines; and 5) Implementing and revising the support plans as required. Family-centred PBS plans consist of: a) approaches for teaching as well as growing skills which are designed to change the problem behaviours; b) Approaches for avoiding the problems before they will happen; c) Techniques for working with the difficulties if and when they do occur; and d) Approaches for monitoring improvement (Binnendyk & Lucyshyn, 2009; Lucyshyn, et al., 2002).

According to Marshall and Mirenda (2002), these kinds of programs have the potential to produce considerable long-term alterations in behaviour resulting in an enhanced standard of living for children with ASD and their family. Boettcher et al. (2003), for instance, offered a family-wide PBS program to the family of a child with ASD within a period of possible crisis. The program resulted in a decrease in disruptive behaviours between children with ASD and their siblings, as well as other family-wide collateral positive effects, such as reduced parental stress and elevated positive relationships between members of the family (Boettcher, et al., 2003).

2.3.4 Family Support Group Programs

Families of children with ASD have special concerns and frequently need a lot of information, for instance, information about ASD, healthcare services, school services, funding sources, local policies, therapy, and much more. ASD support groups may assist parents for many reasons, but mainly they provide parents with a location and a forum to share their experiences, to offer and obtain emotional assistance, and to work as a team to handle common issues (Roberts, et al., 1991). There are many different kinds of ASD support groups depending on the group's focus and objectives. Standard activities include providing shared support and developing new social relationships, disbursing information and providing a family resource centre (Whiaker, 2002). Parents can also benefit from professional support and guidance in identifying good behavioural and teaching practices (Frea & Hepburn, 1999).

In the literature, some studies identify that the structure of support groups is an important factor in their success. Papageorgiou and Kalyva (2010) argued that when
organising and operating support groups for parents of children with ASD, that parent needs, reasons for attending, and expectations should be taken into consideration. There are a few Arabic examples of support and training programs for parents. Ergün-Teğınalp and Akkın (2004) conducted a quantitative and qualitative study at a private special education Centre in Ankara, Turkey. The aim of this program was to help parents of children with ASD to develop positive or adaptive coping styles. The researchers also used this group of mothers of children with ASD in preschool age to investigate the effects of a coping skills education program on the mothers’ stress and hopelessness levels. They measured these levels by adopting the Coping Strategy Indicator Scale (CSI) (Amirkhan, 1990) and the Beck Hopelessness Scale (BHS) (Ergün-Teğínalp & Akkın, 2004). The participants in the study were 20 mothers of children with ASD in preschool age. One intervention group and one control group were comprised of 10 mothers each. The program consisted of eight sessions and ran for four weeks. The sessions followed a format of instruction, discussion, sharing and application of the techniques. Mothers in the intervention group were interviewed after completion of the program to get some qualitative data concerning the effectiveness of the program. The outcomes indicated that after participation in this program, the mothers could coach themselves to look at difficult situations differently and this new set of cognitive responses may have helped them to be more relaxed in difficult situations. However, the results of this study were limited because long-term follow up data were not gathered.

Although there is a deficiency in support programs and training for parents of children with ASD in Jordan, some researchers have attempted to research this area. The results of a study in Jordan showed that a training program had a positive effect in modifying parental attitudes toward their children with ASD (Asaod, 2008). Asaod’s study aimed to investigate parents’ attitudes toward their children with ASD and the differences in these attitudes in regard to the parents’ gender and education level. The study investigated the effects of a support and education program for 20 parents of children with ASD in school age in Jordan. The program aimed to enhance parental attitudes toward their children and to provide parents with information about ASD and how they can deal with their child’s behaviour. The program consisted of 12 sessions over 3 weeks. Based on the study results, the researcher recommended that there is a deficiency in training and support programs in Jordan for parents of children with ASD and a need to develop more programs for parents. However, this program only provided parents with information about children with ASD without including skills for parents such as problem solving, positive thinking and developing social support.
A recent international evaluation of what works in parenting support conducted by Moran et al. (2004) reported outcomes for children, parents and families. Moran et al. (2004, p. 21) described parenting support as “any intervention for parents aimed at reducing risks and promoting protective factors for their children, in relation to their social, physical and emotional well-being”. In almost all evaluations, it was found that parents felt satisfied with the programme they had received. Examples of outcomes from parent education and support programs, such as parent stress and coping, are explored in the next section.

2.4 Outcomes from Parent Education and Support Programs

Guralnick (2011) provides a framework to show how family and environmental factors influence the development of a child with a disability. Guralnick stated that this framework can provide an understanding about the current form of Early Intervention programs and can help to create more comprehensive and effective programs. Guralnick’s framework considered parenting a child with disability as a risk factor for developing stress in parents, while family resources such as effective coping strategies and material resources such as adequate social and financial support can serve as protective factors (see Figure 2.2).

![Figure 2.2: Guralnick’s framework](Guralnick, 2011, p. 14)

The next section examines the effects of family stress and coping within the mesosystem of Bronfenbrenner’s model, while the final section will examine the broader social and cultural factors associated with the macrosystem of Jordanian society.
2.4.1 Parenting Stress and Coping

Many studies have concluded that parents of children with ASD are likely to experience more stress than parents of children with other developmental disabilities (Asaod, 2008; Davis & Carter, 2008; Ergün-ünler-Tekinalp & Akkök, 2004; Hassall, et al., 2005; Hastings & Johnson, 2001). Parenting a child with ASD is particularly stressful because children with ASD typically have a restricted ability to relate to others and understand the world around them. They may also display challenging behaviours that affect everyday family life. Research has shown that parents of children with ASD show a characteristic stress profile which includes stress related to the child's uneven intellectual profiles, pervasive disruptive behaviours and long-term care (Koegel, et al., 1992; Moes, 1995). According to (McBride, 1989) parenting stress is a result of differences between a parent’s expectations about their child, compared to what the parent actually experiences. Based on this view, the larger the disparity between the perceived situational demands and the parent’s resources and expectations, the more stressed a parent can feel.

Davis and Carter (2008) conducted a study to examine factors which are associated with parenting stress among parents of children newly diagnosed with ASD. The study provides evidence that high levels of stress are present in parents who are raising a child with ASD. The results of the study showed that different characteristics of children’s behaviours were predictive of parenting stress. Furthermore, in respect to predictors of stress, the study found that the degree to which child behaviour problems and child competencies are perceived as stressful varied between mothers and fathers. Specifically, the mothers reported more stress than the fathers. The most significant predictor of parenting stress for both mothers and fathers was delays or deficits in the child’s social skills.

The results of research carried out on different groups showed that emotion-oriented designs of coping (e.g. engaging in ruminating, blaming oneself) is positively related to having health conditions for instance anxiety, depression and somatic disorders, while task-oriented coping (active approach to problem-solving) is negatively related to those health conditions (Cohan, Jang, & Stein, 2006). Coping methods are often employed by parents of a child with ASD to reduce the anxiety experienced in everyday situations that cannot be managed in common ways (Cohan, et al., 2006).

A number of studies have reported positive effects from coping skills training programs for mothers of children with intellectual disabilities. Hassall et al. (2005) conducted a study in southeast England with 46 mothers. They found that their coping skills training program
which aimed at assisting mothers of children with ASD to understand stress and its effects, produced positive results on the stress levels and degree of hopelessness reported by the mothers. The intervention methods utilized in this training program consisted of discussions about general coping techniques, creating social support, the development of relaxation skills, positive thinking and problem solving skills (Hassall, et al., 2005).

Ergüner-Tekinalp and Akkök (2004) adopted the Coping Strategy Indicator Scale (CSI) and Beck Hopelessness Scale (BHS) to address the effects of their coping training program for parents of children with ASD in Turkey. The participants in the study were 20 mothers of children with ASD. The aim of this program was to help parents to develop positive or adaptive coping styles. The researchers used two groups (an experimental and a control group) to explore the effects of a coping skills training program on the stress and hopelessness levels of mothers of children with ASD. Each of the experimental group and control group consisted of 10 mothers. The responses of the CSI and BHS scales were analysed on the total scores. The results demonstrated no significant difference between the scores of the experimental and control groups on the pre-intervention administration of the scales. On the other hand, analysis of the post-intervention results indicated that there was a significant difference between the control and experimental groups with the experimental group showing higher social support as a coping strategy and a lower level of hopelessness than the control group.

As will be discussed in chapter three, the Coping Strategy Indicator Scale (CSI) employed by Ergüner-Tekinalp and Akkök (2004) was used in the current study along with the Parent Stress Index (PSI) Scale (Abidin, 1995) to examine the effects of a parent education program conducted for mothers of children with ASD in Jordan.

2.5 Cultural Norms and Disability in Jordan

According to Bronfenbrenner’s (1979) model the macrosystem is comprised of socio-cultural factors which may influence individuals, families, centres and schools in a society. Socio-cultural factors include social values, cultures and attitudes, and may also cover race, social status and gender (Johnson, et al., 1992). Several studies have investigated the influences of social cultural factors on children’s behaviour. For instance, Pinderhughes, Nix, Foster, and Jones (2001) found that social services and social networks which provide support for parents tend to offer a more nurturing environment for children. In the current study, societal attitudes towards disability in the Jordanian culture were investigated in order
to examine the impact of socio-cultural factors on the families of children with ASD and what impact this may have on the effectiveness of the parent education program.

Essentially, “cross-cultural differences in the interpretation of disability show that the lives of people with disabilities are made more difficult not so much by their specific impairment as by the way society interprets and reacts to disability” (Peters, 2009, p. 756). The impact of cultural perceptions of people with disabilities needs to be taken into account in any discussion of intervention outcomes (Nagata, 2003). Every disability is perceived differently by society and different cultures may define and relate to a given disability in different ways (Barnes & Mercer, 2001).

Jordan is one of the Arab countries that is recognized by the international community in promoting disability rights (Rutherford, 2006). In Jordan, the law emphasizes that individuals with disabilities are entitled to equal education, training, work, and care (Ministry of Education, 1998). Legislation can enforce the provisions of educational opportunities for individuals with disabilities in terms of physical access, but it is difficult to enforce within a society acceptance of people with a disability. Therefore, it is important to determine the attitudes of people in Jordanian culture towards individuals with disabilities.

A survey carried out in Jordan, Yemen and Egypt estimated that in these countries between 5% and 10% of children under age 18 years old have at least one type of disability; many of these children confront educational, health, psychological, and social problems (Bank, 2005). Education is one area in which children with disabilities are most disadvantaged. Children with disabilities, specifically females, tend to be far more likely to be illiterate compared to other groups in the Arab region. A study that assessed the attitudes of Arab teachers towards individuals with disabilities found that teachers in general have negative attitudes towards individuals with disabilities (Alghazo, Dodeen, & Algaryouti, 2003). Alghazo, et al. (2003) found that the academic background of educators had an impact on their perceptions towards individuals with disabilities. Educators from the colleges of humanities and education had more positive perceptions towards students with disabilities compared to the educators from the college of science. This may be due to the fact that it is compulsory for educators from both the college of humanities and the college of education to have courses that relate to educational approaches for personal differences and student characteristics, while educators from the college of science are not required to study these topics (Alghazo, et al., 2003).
A study in Lebanon to evaluate age-matched siblings showed that individuals with disabilities were more likely to experience disadvantage in areas of employment, education, income, and marital status, compared to their non-disabled siblings. A study by Shaar and McCarthy (1992) showed that the most disadvantaged area for individuals with disabilities was marital status in lower-income groups for males and in socioeconomic groups for females.

In some Arab cultures, a child with a disability might be sent to school and given support that greatly diminishes the influence of the impairment, while in other Arab cultures, a child with a disability is seen as not only a misfortune, but as shameful and embarrassing (Nagata, 2003). Although children with disabilities are generally accepted within families, a study in Israel investigating Arab parental perceptions of their child with a disability reported a perceived sense of shame and rejection by society and thus parental concealment of children with a disability was common (Shurka & Florian, 1983).

Another study of parental attitudes toward their children with disabilities among families living in Israel reported that although attitudes were generally quite positive, better educated parents tended to hold more favourable attitudes than those with less education (Reiter, Mar‘i, & Rosenberg, 1986). Another study in Israel explored stress and coping in parents (particularly mothers) of children with disabilities. Consistent with data from other Arab countries, these studies suggested that mothers provide the major burden of caretaking for children with disabilities (Kandel, Morad, & Vardi, 2004). Other findings of a study with Arab mothers of children with intellectual disability who lived in northern Israel showed that the presence of informal support (friends, family and community) is a more important factor in ameliorating maternal stress than any other single factor, including formal sources of support, such as welfare services (Duvdevany & Abboud, 2003).

The literature has revealed that one of the most important predictors of successful integration of children with disabilities in society is the attitude of general education parents and professionals (Alghazo, et al., 2003; Reiter, et al., 1986). Some study results indicated that attitudes held by parents and professionals towards children with disabilities determine the success or the failure of inclusion (Mikus, Fialka, & Feldman, 2012; Wilczenski, 1993). If parents or professionals hold a positive attitude towards individuals with disabilities this allows and encourages the establishment of policies that ensures the children’s right to be educated, whereas negative attitudes towards individuals with disabilities can limit their opportunities to be educated (Asaod, 2008; Jamieson, 1984).
2.6 Literature Review Summary

The literature review showed that education and training programs are considered one of a handful services in supporting parents of children with ASD (Asaod, 2008; Erg"uner-Tekinalp & Akk"ok2, 2004; Gross, et al., 1995; McConachie, et al., 2005; Roberts, et al., 1991). The research was examined for evidence to support best practice education and training programs in supporting parents of children with ASD to help them to increase understanding about their child’s behaviour, improve their coping skills and reduce their stress levels. The literature showed that parent education and training programs for parents and families have focussed on increasing parent knowledge of ASD and in building parental competence and confidence. The literature review also showed that parent education and training programs give parents useful skills such as understanding stress and its effects, general coping strategies, problem solving skills, positive thinking and developing social support that they can use in the long term. Parents of children with ASD need information about ASD to reorganize their lives toward a positive coping style. However, in Jordan the interventions for children with ASD tend to focus mostly on the child; the parents have few opportunities to get help or support (Asaod, 2008). For this reason it is important to explore whether the provision of an education program in Jordan for mothers of children with ASD will help to improve the parents’ coping skills and enhance understanding about their child’s behaviours. Effective programs can help parents feel less overwhelmed by their difficulties and more hopeful for the future. The next chapter describes the conceptual framework guiding the present research and the methods and instruments utilised in this study.
Chapter 3: Methodology

3.1 Overview

Chapter 3 presents the conceptual model underlying the research project and an explanation of the quantitative and qualitative methods employed to investigate the experience of parenting a child with ASD in Jordan and the effectiveness of a parent education program implemented in the capital city of Jordan, Amman. The conceptual model, based on Bronfenbrenner’s ecological systems theory and a family-centred approach to early intervention, is first described, followed by the research questions. The next section presents a description of the mixed method approach followed by information about the participants and details of the data collection and analysis procedures.

3.2 The Conceptual Model

The present study used three elements of Bronfenbrenner’s ecological system to develop a conceptual model. These elements are the microsystem, mesosystem and macrosystem. The microsystem consists of the nuclear family, that is, the parents and their child. The next level is the mesosystem which consists of the child’s interactions in environments outside the family home, such as child-care settings or school. The family is the most influential part of the mesosystem because the influence of the family extends to all aspects of the child’s development. In the early years of life children are dependent on their immediate care-givers, typically their family, to provide better cognitive and social development, nutrition, security and health (Moore, 2006). While the exosystem contains the immediate supports available to families, such as extended family members, friends and the workplace and neighbourhood, the main focus of this study was the mesosystem with a particular focus on the families of young children with ASD in Jordan. The study included the implementation of an education program for mothers to help them improve their knowledge about ASD and how this condition affects their child’s behaviour. The program also aimed to increase the mothers’ skills and reduce their stress levels. According to Bronfenbrenner’s (1979) model, improvements in family functioning have a flow-on effect to children’s progress and well-being. The effects of the macrosystem were also included. Bronfenbenner states that the socio-cultural factor includes cultures and social values that influence every layer in the ecological system. In this study, the macrosystemic aspect that was included was societal attitudes towards disability in the Jordanian culture.
The conceptual framework depicted in Figure 3.1 was used to guide the research questions, the methodology and reporting of the collected data. The specific research questions were:

1. How do Jordanian mothers experience parenting a child with ASD?
2. Are there differences between mothers’ and fathers’ coping skills and stress in families with a young child with ASD?
3. What effects does a training program have on the coping skills and stress of mothers of children with ASD?
4. How is disability regarded in the Jordanian culture by parents and professionals?

![Figure 3.1: The conceptual model for the study based on Bronfenbrenner’s ecological theory](image-url)
3.3 Research Methods

This study is situated within a qualitative and quantitative framework. Langenbach, Vaughn, and Aagaard (1993) state that qualitative researchers “are interested in an extensive understanding of their participants’ or informants’ world…” (p. 92). Qualitative research focuses on emergent themes in the data where understanding of a particular phenomena develops out of a grounded theory, as opposed to proving or disproving a pre-existing theory in quantitative research (Wiersma & Jurs, 2005). Qualitative research provides an opportunity for the researchers to hear the personal needs and events in the form of storytelling (Pugach, 2001). Further, according to Pugach, qualitative research emphasizes, “understanding the complexity of a situation and enabling a fuller consideration of the phenomenon under study” (p.440). Following a constructivist approach acknowledges and encourages the relationship between the researcher and participant, the conversation between the two is reciprocal and evolves with a common understanding (Guba, 1990). Constructivist research does not attempt to prove or disprove a-priori theories or notions, rather its “aim is to distil a consensus construction that is more informed and sophisticated than any of the predecessor constructions” (Guba & Lincoln, 1994, p. 111). For this study, the meaning making practices of a constructivist approach such as in-depth interviews and focus groups were employed in order to acquire a deeper understanding of the experiences of parents of children with ASD in the context of Jordanian culture.

The in-depth interviews involved pre- and post-intervention interviews. Pre-intervention interviews were conducted with 10 mothers of children with ASD before the mothers commenced a parent education program and post-intervention interviews with the mothers were carried out at the conclusion of the education program. Two focus groups were conducted with the 10 husbands of the mothers and another two focus groups were conducted with 10 professionals who were involved in the care and education of the children with ASD. The interviews and focus groups were conducted to allow the researcher to explore the experiences of families of children with ASD in the Jordanian culture and to investigate the ways in which these families were either stressed or supported by their immediate networks (exosystem) and by broader societal attitudes and services (macrosystem). In the interviews and focus groups, the participants were treated as conversational partners and the questions flowed from the previous answers. While a list of questions was used to guide the researcher, they were asked when they fitted into the conversation. Rubin and Rubin (1995) describe this type of interview as “flexible, iterative, and continuous” (p. 43). Flexibility permitted the
researcher to respond to the nuances of the participants. There was a cyclical nature to the interviewing process as the mothers were interviewed before and after the intervention. With each interview the researcher was gathering, analysing, and forming smaller units of meaning. In this study, the qualitative study was the major component and it was supported by quantitative data. The quantitative data were obtained from the mothers and fathers by a questionnaire comprised of two scales assessing coping skills and stress. Questionnaires assessing parent coping skills and stress levels were chosen for the quantitative measure because previous studies have indicated that these aspects are important to child and family well-being and also because previously developed and validated scales have been used to measure changes in parent stress and coping skills (Daniels, 1999; Davis & Carter, 2008; Ergüner-Tekinalp & Akkök, 2004; Hassall, et al., 2005; Lazarus, 1984; Reece & Harkless, 1998; Tunali & Power, 2002).

The questionnaire was administered to the mothers before commencing the implementation of the parent education program and the same scales were re-administered at the conclusion of the education program to evaluate the effects of the program. The same questionnaire was also administered to the 10 fathers before the focus group discussion commenced.

### 3.4 Participants

This study involved interviews with 10 mothers and focus groups with 10 fathers of pre-school age children with ASD as well as focus groups with 10 professionals involved in the care and education of the children. While the sample size was small, other researchers have found that small interview samples can be adequate in supplying accurate results (Guest, Bunce, & Johnson, 2006; Romney, Weller, & Batchelder, 1986). Guest et al. (2006) carried out sixty in-depth interviews with females in two West African countries in order to find the degree of data saturation and variability. They found that saturation happened within the first twelve interviews, despite the fact that basic elements for reactions were present as early as six interviews. Variability within the data followed similar patterns. Romney et al. (1986) computed in which samples as small as four individuals can provide accurate information with a high confidence level as long as the participants possess a high degree of familiarity with the domain of inquiry (p. 326).

The 10 mothers were also participants in a parent education program conducted in Jordan by the researcher. The selection of only 10 mothers to participate in the parent
education program can be justified by previous literature which has found this number was reasonable to obtain significant results from a parenting program (Ergün-Tekinalp & Akkök, 2004). One of the advantages of a small group is that small groups make contact between the group members easier (Abdel-Fattah Clamili, 1988). Furthermore, because the study targeted both mothers and fathers from the same family it would have been difficult to find more than this number of participants from the same family in a small country like Jordan.

The study was conducted in two private centres for children with disabilities. These centres were the Consultative Centre for Autism and the Communication Centre for Autism, both located in Amman, Jordan. Amman is the capital and largest city of Jordan, and has the main centres of political, cultural and commercial. Amman has a population of 2,85 million as of 2011 (Department of Statistics, 2011). The two centres provide services and programs predominantly to support individuals with disabilities (including children with ASD) and limited support to families. The services on offer include the provision of educational programs for children with ASD, an ASD helpline for parents and caregivers, specialist assessments and diagnosis, and consultancy services for professionals and organizations working in the field of ASD. Ten parents of pre-school age children with ASD were chosen randomly from the number of parents whose children were being educated in these two special education centres. Because a primary goal of the study was to examine both mothers’ and fathers’ perspectives, participants were limited to couples where both mothers and fathers agreed to participate in the project. As previously discussed, five parents were selected from each centre as they provided a manageable number of interviews to conduct and analyse, as well as providing scope for variety in the responses.

3.5 Data Collection

The researcher contacted both Centre Directors and invited them to participate in the study (Appendix 1.1). Following their informed consent (Appendix 2.1) the Directors were asked to send an information statement (Appendix 1.3) and consent letter (Appendix 2.3) to the staff working in their centre and to all the parents (Appendix 1.2, Appendix 2.2) in their centre who had a preschool aged child with Autism inviting the parents and professionals to participate in the research project. In this study, a total of 16 mothers and their husbands and 13 professionals were invited to participate in the research project by sending them the information statement and the consent letter. The information statement described the project.
aims and what would be expected from them. It assured the potential participants of the confidential and voluntary nature of their participation. If the parents and professionals were willing to participate in the project they were asked to sign a voluntary consent letter to indicate their consent. Twelve mothers and their husbands and 10 professionals agreed to participate. The names of 10 mothers and their husbands were randomly selected from the 12 couples who had agreed to participate in the project. Those parents not selected were thanked for their interest and provided with written information on ASD. All 10 professionals who provided consent participated in the project.

3.6 Procedure

In this study there were three phases of data collection. The first phase was the pre-intervention interviews with 10 mothers of children with ASD. Mothers were interviewed because the mothers in Jordan, as in most Arabic countries, take the most responsibility for childcare and spend more time with their children than do fathers. At the pre-intervention interview the coping scale (Appendix 3) (Amirkhan, 1990) and stress scale (Appendix 4) (Abidin, 1995) was also administered. The mothers were asked to answer the scales before the pre-intervention interviews commenced. Mothers were interviewed about their understanding of disability and their experience of parenting a child with ASD (see Appendix 5.1). All 10 mothers gave permission for the interviews to be audio recorded and for the researcher to take hand-written notes. The completion of the scales and the pre-intervention interview took about 60 minutes with the shortest interview lasting 40 minutes and the longest interview taking 60 minutes. The nature of the pre-intervention interviews, the interview questions and the two scales are described in more detail in later sections of this chapter. The pre-intervention interviews provided data to answer the first and fourth research questions: How do Jordanian mothers experience parenting a child with ASD and, How is disability regarded in Jordanian culture by parents and professionals.

The fourth research question was also informed by data collected from focus groups during the second phase of the study. There were a total of 4 focus groups which were conducted with the 10 husbands of the mothers who were interviewed and with 10 professionals working at the centres. There were two focus groups of five fathers each and two focus groups with five professionals from each centre. Of the 10 professionals 6 were teachers, 2 were speech pathologists, and 2 were administrators. The aim of the focus groups was to discuss how disability is regarded in Jordanian culture from the parents’ and
professionals’ perspective. At the beginning of each focus group meeting the fathers were also asked to complete the study scales. The results of the scale scores of the fathers and the results of the scale scores of the mothers were used to compare whether there were any differences between mothers and fathers regarding their levels of stress and their coping skills in response to Research Question 2. The nature of the focus groups is described in more detail in section 3.7.2 of this chapter.

The education program was implemented for the 10 mothers. The education program was conducted by the student researcher and consisted of four sessions. As reported in the literature this number of sessions is considered reasonable and effective for running an education program (Abdel-Fattah Clamili, 1988). One session was conducted each week for 4 weeks and each session was approximately four hours long (see section 3.9).

The final phase of data collection was conducted after the education program had finished. Post-intervention interviews were conducted with the mothers who had previously been interviewed and participated in the program. Because mothers’ feelings about the effectiveness of the program were examined in this interview, the post-intervention interviews were conducted by an objective person to ensure that mothers were not influenced by their relationship with the student researcher. The engagement of an unknown and objective interviewer helps to improve the credibility of the study (Kvale, 1996; Liamputtong & Ezzy, 2005). The post-intervention interviews aimed to investigate how mothers responded to the education program and whether the program led to improved mothers’ understanding of their children’s behaviours. In addition, the two scales were readministered to the 10 mothers. These scales were administered to investigate if there was any change in the mothers’ coping skills in order to answer the third research question: What effects does a training program have on mothers of children with ASD including coping skills and stress?

3.7 Research Instruments

This section introduces the instruments that were used in the data collection for this research. Three types of qualitative data were collected: pre and post-intervention interviews with 10 mothers of children with ASD; focus group interviews with 10 fathers of children with ASD; and focus groups with 10 professionals from the special education centres. The quantitative data comprised the scales to measure the coping skills and stress levels of the parents. All instruments were translated into the Arabic language in order to avoid language
barriers (see Appendix 7). Table 3.1 shows the research questions in relation to the research instruments.

**Table 3.1: Research questions in relation to research instruments and participants**

<table>
<thead>
<tr>
<th>Research question</th>
<th>Research instrument</th>
<th>Study phase</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How do Jordanian mothers experience parenting a child with ASD?</td>
<td>• Pre-intervention interviews (Q1-7,Q10,Q12-14,Q17-22)</td>
<td>• First phase: qualitative data</td>
<td>10 mothers</td>
</tr>
<tr>
<td>2. Are there differences between mothers’ and fathers’ coping skills and stress?</td>
<td>• Pre – Scales Coping Strategy Indicator (CSI)</td>
<td>• First phase: quantitative data</td>
<td>10 fathers</td>
</tr>
<tr>
<td></td>
<td>• Pre-Parent Stress Index (PSI)</td>
<td></td>
<td>10 Mothers</td>
</tr>
<tr>
<td>3. What effects does a training program have on mothers of children with ASD including:</td>
<td>• Education program</td>
<td>• Second phase: qualitative data</td>
<td>10 mothers</td>
</tr>
<tr>
<td>a- Coping skills.</td>
<td>• Post- intervention interviews (Q1-7)</td>
<td>• Final phase: qualitative data</td>
<td></td>
</tr>
<tr>
<td>b- Stress.</td>
<td>• Pre, Post CSI &amp;PSI scales</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How is disability regarded in Jordanian culture by parents and professionals?</td>
<td>• Focus groups</td>
<td>• Second phase: qualitative data</td>
<td>10 mothers</td>
</tr>
<tr>
<td></td>
<td>• Pre-intervention interviews (Q8,9,11,15,16)</td>
<td>• First phase: qualitative data</td>
<td>10 fathers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>10 professionals</td>
</tr>
</tbody>
</table>

All research phases were conducted by student researcher except the final phase (post-intervention interviews) that was conducted after the education program had finished. Because mothers’ feelings about the effectiveness of the program were examined in this interview, the post-intervention interviews were conducted by an objective person to ensure that mothers were not influenced by their relationship with the student researcher. The engagement of an unknown and objective interviewer helps to improve the credibility of the study (Kvale, 1996; Liamputtong & Ezzy, 2005). With each research phase the researcher was gathering, analysing, and forming smaller units of meaning. To reduce the self reports limitations the researcher was participant-observer for all the data collection stages (Iacono, Brown, & Holtham, 2009).
3.7.1 In-depth Interviews

“An in-depth interview is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation” (Liamputtong & Ezzy, 2005). It can result in increased insight into individuals’ feelings, thoughts, and behaviour on important concerns. In this study interviews were conducted with 10 mothers of pre-school age children with ASD before and after the mothers participated in an educational program.

The pre-intervention interviews were held before commencing the implementation of the education program. The interviews took around one hour. In the pre-intervention interview, background and demographic information was obtained about the mothers of children and the two scales for coping strategies and stress levels were administrated. The interview protocol included several questions that focused on how the Jordanian culture regards children with ASD, and how Jordanian mothers’ experienced parenting a child with ASD (see Appendix 5.1). At the beginning of the interviews some mothers found it hard to talk about their experiences and feelings about their child with ASD. However, after talking with the interviewer about the project objectives and the expected results all mothers felt comfortable and were willing to share their experiences and feelings. There were only three cases where the mothers became upset and started to cry when they remembered the time of their child’s diagnosis of ASD. When the mothers became upset the researcher spoke comforting to them and gave the mothers an opportunity to cease the interview. Each of the three mothers who initially became upset were soon consoled and each indicated that they wanted to continue with the interview.

The post-intervention interviews were carried out after implementation of the education program. These interviews focused on investigating the mothers’ response to the education program and whether the program led to improved mothers’ understanding about their child’s behaviours.

The questions of both of the pre and post-intervention interviews were prepared in advance (see Appendix 5). The interview framework comprised a series of open-ended questions, allowing participants latitude to provide a depth of information they desire to provide (Stewart, Shamdasani, & Rook, 2006). The interview framework was designed to gain an answer to the first two research questions; how is disability regarded in Jordanian culture by parents and professionals, and how do Jordanian mothers experience parenting a child with ASD.
3.7.2 Focus Groups

A focus group interview is a structured group procedure accustomed to acquire detailed information about a particular subject (Basch, 1987). Focus groups typically investigate a range of ideas and feelings that individuals have about certain topics (Rabiee, 2004). Focus groups usually consist of homogeneous individuals representing a particular section of the population.

The present study involved two sets of two focus groups and each session was conducted by the student researcher. The focus groups were conducted in a private room at the private centre for children with disabilities. This centre was the Communication Centre for Autism, located in Amman, Jordan. The focus groups were carried out after completion of the pre-intervention interviews for mothers. The focus groups were conducted during the centres working hours on the days when there were no education program sessions. The first set of focus groups was with 10 fathers of children with ASD as discussed above. The focus group with the fathers was run in two groups and each focus group was composed of five fathers. The aim of these focus groups was to determine how disability is regarded in Jordanian culture from the fathers’ perspective. Focus groups were selected rather than interviews for the fathers as the aim was to encourage the participants to share suggestions and perceptions with one another and thus generate a range of possible suggestions, ideas and feelings related to how disability is regarded in Jordanian culture (Krueger & Casey, 2000). The focus group questions for fathers are presented in Appendix 6.1. These questions focused on how the Jordanian culture accepts a child with a disability, what was the most difficult aspect in Jordanian culture that faced fathers of a child with ASD, and what kind of support families had to help children with ASD.

The second set of focus groups was with 10 professionals from the two private special education centres. The focus group with the professionals were run in two groups and each focus group was composed of five professionals from each centre. Professionals’ focus groups were conducted in the same two private centres for children with disabilities. The focus groups were carried out after completion of the fathers’ focus groups. These focus groups were conducted during the centres’ working hours. The aim of this phase was to discuss how disability is regarded in Jordanian culture from a professional point of view. Each focus group session lasted between one hour and two hours.

In the focus groups for professionals, the constructions for questioning followed general guidelines to facilitate the discussions. The discussion started with general questions
designed to help participants connect, such as questions about their names, their cities and their jobs. The general question was followed by explanatory information about the topic and purpose of the session and then key questions were presented aimed at understanding how the Jordanian cultures accept a child with disability or with ASD, what is the most difficult aspect in Jordanian culture facing the family of a child with disability, and what kind of supports or services do families have to help their child with disability (Appendix 6.2).

3.7.3 The Coping Strategy Indicator (CSI)

The Coping Strategy Indicator Scale (CSI) was developed by Amirkhan (1990). The CSI focuses on measuring situational coping encompassing the strategies of avoidance, problem solving and seeking social support. Several studies have used the CSI with a selection of populations to evaluate coping strategies in a variety of circumstances, for instance, exam-related coping and reactions to racial discrimination (Ptacek, Smith, Espe, & Raffety, 1994), coping reactions associated with spouses of depressed patients (Baird & Peterson, 1997), and individuals with amputations (Garguilo & Kilgo, 2000). These studies commend the psychometric robustness of the CSI compared to other coping assessments.

The CSI (Amirkhan, 1990) is comprised of 33-items regarding how often in the past six months the respondent exhibited the behaviours on the CSI scales. The responses are measured by means of a 3-point Likert scale: a lot (3); a little (2); or not at all (1). The CSI has three subscales which each contain 11 items. The three subscales are Problem Solving, Seeking Social Support, and Avoidance (Amirkhan, 1990). Problem solving involves an instrumental, problem-oriented approach to active management of stressors and includes items such as “In the past six months how often have you…formed a plan of action in your mind”. Seeking Social Support relates to the basic human need for human contact or reaching out to others for comfort or advice and includes items such as “In the past six months how often have you…Sought reassurance from those who know you best”. Avoidance is defined as the purposeful attempt at withdrawal or distraction involving physical and/or psychological withdrawal, for example, through distraction or fantasy. The highest score on each sub-scale is 33 and the lowest score is 11 (see Appendix 3). High scores for the first two subscales, problem solving and exploring social support indicate that positive coping strategies are frequently used. In this study all items on the Avoidance subscale were reverse scored to be consistent with the other two subscales, so that higher scores indicate better coping mechanisms while lower scores indicate greater avoidance or withdrawal.
Cronbach’s alpha coefficients of the scale and subscales obtained in previous research have indicated that the CSI is a reliable measure of parent coping (Amirkhan, 1990; Desmond, Shevlin, & MacLachlan, 2006). The Cronbach’s alpha coefficients reported by Amirkhan (1990) and Desmond et al. (2006) have indicated adequate internal consistency for each of the subscales ranging from 0.86 to 0.98 for Problem Solving, 0.89 to 0.98 for Seeking Social Support and from 0.77 to 0.96 for Avoidance. According to Amirkhan (1990) and Desmond et al. (2006) the total Cronbach’s alpha coefficients for the complete CSI scale ranged between 0.86 and 0.92. For the present study the value of the reliability coefficient for the total scale score ranged between 0.88 and 0.91 indicating adequate internal consistency.

3.7.4 The Parent Stress Index (PSI)

The Parent Stress Index (PSI) Scale (Abidin, 1986) was used in this study to measure the stress level in parents of children with ASD. It is often used with parents of children who may have behavioural or emotional problems (Abidin, 1995). A study by Dumas, Wolf, Fisman and Culligan (2006) to determine the stress levels of parents of children with ASD and behaviour problems using the PSI indicated that the parents of children with ASD experienced statistically and clinically higher levels of stress compared to parents of children with behaviour problems or depression. High internal consistencies for this scale are typically reported (Reitman, Currier and Stickle, 1988). For the present study the value of the reliability coefficient for the total scale score ranged between 0.83 and 0.92 indicating adequate internal consistency.

The PSI short form (Abidin, 1995) used in the present research is a direct derivative from the full-length Parenting Stress Index test. The short form consists of 36 items (see Appendix 4). All the items on the short form are answered using a 5-point Likert scale (from 1 = strongly agree to 5 = strongly disagree). The total stress score provides an overall indication of parenting stress that a parent is experiencing. A parenting stress total raw score of ≥ 90 strongly indicates significant stress in the parent–child relationship and indicates that parents and their child should seek professional counselling (Abidin, 1995). There are three subscales and each is comprised of 12- items. The three subscales include parental distress, parent-children dysfunctional interaction, and difficult child. The items for each sub-scale are included in Appendix 4.

Parental Distress (PD) measures distress directly related to parenting a child who is sick or impaired. More specifically, PD assesses parenting competence, restrictions on other life
roles, conflicts with the child’s other parent, lack of social support and the presence of depression. Parent-children dysfunctional interaction (PCDI) measures the parent’s perception that his or her child does not meet the parent’s expectations, and that the interactions with his or her child are not reinforcing to him or her as a parent. In general, the parental description of the parent–child relationship suggests either that the parent sees him- or herself as abused by or rejected by the child, or that he or she was disappointed in and felt alienated from the child. The Difficult Child (DC) subscale measures basic behavioural characteristics of children that make them either easy or difficult to manage. These characteristics are often rooted in the temperament of the child, but they also include learned patterns of defiant, non-compliant and demanding behaviour. The PSI scale and the three subscales are particularly relevant for parents of children with ASD because of the significant social and behavioural difficulties typically presented by most children with a diagnosis of ASD.

3.8 Data Analyses

3.8.1 Analysis of the Qualitative Data

Content analysis was conducted to analyse the data from the pre and post-intervention interviews and focus groups. Content analysis was conducted separately for the interviews and focus groups. The mothers’ pre-intervention interviews were analysed separately to the mothers’ post-intervention interviews, while the transcripts from the focus groups for fathers and professionals were combined to form one data set.

Content analysis was chosen as it fitted most closely with the aims of the study. Content analysis is defined as the process of identifying the main substantive points in an interview or focus group transcript and categorising them (Liamputtong & Ezzy, 2005). NVivo software was used for identifying the main substantive points emerging from the qualitative data. NVivo supports “fine grained analysis” of chunks of a message along with the whole message (Gibbs, 2002, p. xxiii). It also supports “speed coding” (Gerbic & Stacey, 2005). Rubin and Rubin (1995) present an approach to analysing data that involves three main steps: coding the data, grouping it into categories, and finally grouping the information into themes. In order to begin the coding process, the researcher read every interview transcript, closely examining them for “core ideas and concepts, to recognize emotive stories, and to find themes” (Rubin & Rubin, 1995, p. 229). Once the early concepts and themes were identified, the researcher created codes to group similar items together. When all the coding
was complete, the researcher grouped the information according to the codes. These groupings allowed analysis of the themes within a category and across categories. The final stage of analysis was to describe and interpret the major findings from the interviews and focus groups.

### 3.8.2 Analysis of the Quantitative Data

The analysis of the quantitative data was intended to measure and compare the stress and coping levels for mothers of a child with ASD using the Parenting Stress Index (PSI) and the Coping Strategy Indicator (CSI) scales before and after the education program (Research Question 3). Quantitative analysis was also employed to compare the stress and coping levels of mothers with fathers (Research Question 2). The findings from the analysis of the quantitative data were reported separately to answer Research Questions 2 and 3, but these results were also interpreted in light of the deeper insights provided by the analysis of the interviews and focus groups.

Nonparametric tests were used in this study owing to the small sample size and the non-normal distribution of the data. Nonparametric, or distribution free, tests refer to a statistic that does not require the assumption of normality or the assumption of homogeneity of variance. They compare medians rather than means. Nonparametric tests are “fewer and weaker than those associated with parametric tests” (Siegel & Castellan, 1988). However, nonparametric tests are often used in place of parametric tests when one feels that the assumptions of the parametric test have been too grossly violated (Alan & Wayne, 2006).

The basic technique used by nonparametric procedures to get around the parametric assumption is that they do not use the raw data. Instead, in nonparametric procedures, the ordered or ranked values are used in the analysis (Siegel & Castellan, 1988). This study used the Mann-Whitney U-test to compare the scores of mothers and fathers (independent samples) prior to the education program and the Wilcoxon test to compare the scores of mothers before and after the education program (paired samples).

Sometimes distributions of variables do not show a normal distribution, or the samples taken are so small that one cannot tell if they are part of a normal distribution or not. Using the t-test to tell if there is a significant difference between samples is not appropriate here. The Mann-Whitney U-test can be used in these situations. This test can be used for very small samples (between 5 and 20). The Mann-Whitney U-test was chosen for this study because the sample size was small and the data were not normally distributed.
The Wilcoxon signed-ranks test can be used with two repeated (or correlated) measures and so this test was used to compare the mothers’ scores on the two scales before the education program with their scores after the program. The sign test counts the number of differences that are positive and those that are negative and then makes a decision based on these counts. The Wilcoxon signed-ranks test goes one-step further; it uses information about the magnitude of the differences. Specifically, the absolute values of the differences are ranked from smallest to largest, and then the sum of the ranks associated with positive differences is compared with the sum of the ranks associated with negative differences (Alan & Wayne, 2006).

3.9 The Education Program

The education program was conducted in one session each week for 4 weeks and each session was approximately four hours long. The program was conducted in the two private centres for children with disabilities. These centres were the Consultative Centre for Autism and the Communication Centre for Autism, both located in Amman, Jordan. The program was conducted during the centres’ working hours. The researcher contacted the 10 mothers by phone to organise the sessions’ day, location and a convenient time for them. The mothers used public or private transport to get to the centres. The program was developed, managed and administered by the researcher. The researcher is a psychologist with previous experience as a counsellor at public schools in Jordan. Furthermore, the researcher has completed training in conducting sessions for parents of children with additional needs in Australia. These experiences and training meant that the researcher was well prepared to provide the parent education program and well qualified to be able to manage the risk of any emotional distress arising from the sessions by providing support and advice for parents whenever necessary. The purpose of the first session was to welcome the mothers, introduce them to each other and also to provide an introduction to the education program and general information about the three major areas of impairment associated with ASD (that is, communication, social relations and behaviour). The second session focused on communication difficulties in children with ASD, and social difficulties, such as making friends. The third session discussed repetitive behaviour and the problems with sensory processing faced by many children with ASD. The final session discussed strategies to help children with ASD during play time and also ways to manage children sleeping and eating problems.
The education program framework included a series of presentations (PowerPoint) for each session. Each session included time for discussion among the group members and sharing of ideas and experiences. Participants were encouraged to talk about their experiences, any stress producing conditions in their lives and discuss some of the skills they used to help reduce their own stress.

3.9.1 The Education Program Format:

All the sessions of the education program were delivered with a similar format. This included:

1. Welcome
2. The outline of the topic
3. Sharing of ideas and experiences
4. A PowerPoint presentation on the session topic
5. A discussion of the topic.
6. Questions, Answers, feedback and comments from participants

At each session the participants were seated in a circle so they could easily see each other and see the researcher who led the group. The mothers appeared to enjoy the program sessions and were willing to share their experiences, suggestions and feelings with each other. During each session the mothers were eager to talk to each other and consulted the researcher or other mothers about problems they were facing with their child. Usually, the mothers wrote notes during the sessions and then tried to use the strategies with their children at home. For instance, some mothers tried to apply strategies to manage sleeping and eating problems with their children and in the following session they discussed the outcome of these strategies. There was a morning tea break for half an hour after the first two hours of each session. During the break the mothers were always talking about the sessions’ contents. At the end of the last program session, the mothers had a farewell party to say goodbye to the researcher and also to say goodbye to the mothers from the other centre.

3.9.2 The Education Program Sessions:

The education program was conducted in one session each week for 4 weeks and each session was approximately four hours long. Each program session addressed a specific topic. In the following descriptions, the sources used to prepare the content of each session are indicated in parentheses.
FIRST SESSION: Welcome, introduction to the education program and information about ASD (Autism Research Institute, 2007; Hollander, 2003; Smith, et al., 2007).

1. Build a relationship based on trust between the researcher and members and between members themselves.
2. Definition of the nature of the program and its goals and some of the principles and standards that govern the work of the group.
3. Autism Spectrum Disorder: Definition and characteristics.


1. Introduction.
2. What is communication? How are friendships formed?
3. Characteristics and impact of social and communication difficulties.
4. Strategies to support children with communication or social difficulties.
5. Summary.

THIRD SESSION: Repetitive behaviour and sensory processing (Gense & Jay, 2005; Smith, et al., 2007).

1. Introduction.
2. What is repetitive behaviour? What is sensory processing?
3. Characteristics and impact of repetitive behaviour and sensory processing problems.
4. Strategies to support children with repetitive behaviour or sensory processing problems.
5. Summary.

FOURTH SESSION: Sleeping and eating problems and programs for children with ASD. Helping children with ASD during play time and conclusion (Australian Psychological Society, 2010; Bromley, et al., 2004; Handleman & Harris, 2008; National Research Council, 2001a; Schreibman & Koegel, 1996; Volkert & Vaz, 2010).
1. Introduction of sleeping and eating problems.

2. Strategies to manage sleeping and eating problems

3. Introduction of the importance of play for children with ASD.

4. How to play with a child with ASD.

5. Review of what has been presented in previous sessions.

6. Dissection of any issues arising from previous sessions.

All mothers appeared to be comfortable with the program sessions and they were willing to co-operate fully in the program. All the mothers from the pre-intervention interviews attended every program session. After each program session some mothers continued talking to the researcher and to each other about their own experiences. At the last program session, the mothers said they appreciated the information learned about children with ASD, they appreciated the trust developed between the researcher and mothers and between the mothers themselves, and they appreciated discussion of some of the problems associated with ASD.

3.10 Ethical Considerations

Ethics evaluation of the proposed research was necessary to ensure that the ethical practice in the study was of the highest standard. This evaluation was based on an assessment of the level of risk to participants in conducting the research. Following an approved ethical process ensures that the participants are not pressured to do the research, that their confidentiality is assured, and that they are protected from misrepresentation and exploitation (Cavana, Delahaye, & Sekaran, 2001; Fink, 2008).

The research strictly followed the ethics guidelines provided by The University of Newcastle Human Research Ethics Committee (HREC). A human ethics application and related requirements, such as the study’s questionnaire and interviews, were submitted and approved by HREC prior to commencing the research. The research approval number for the study was H-2011-0215.

3.11 Summary of Chapter

In this chapter, the conceptual model underlying the research project and the methodology used to collect data for the quantitative and qualitative study were described
and justified. Furthermore, information about the participants, details of analysis procedures and ethical considerations were discussed. The conceptual model, based on Bronfenbrenner’s ecological systems theory and a family-centred approach to early intervention was described. The data collection for the quantitative and qualitative study was administered through three phases. The first phase was pre-intervention interviews with 10 mothers of children with ASD who completed PSI and CSI scales and were also interviewed about their experience of raising a child with autism. The second phase involved two focus groups with 10 fathers (who were the marriage partners of the mothers from the first phase) and two focus groups with 10 professionals. At the beginning of fathers’ focus group meeting, fathers were asked to answer the PSI and CSI scales. The second phase also involved an education program for 10 mothers of children with ASD who completed the pre-intervention interviews, PSI and CSI scales. The final phase was post-intervention interviews with the mothers after the education program. At the beginning of post-intervention interviews, the two scales were readministered and the mothers were interviewed again. Content analysis was conducted to analyse the data from the pre and post-intervention interviews and focus groups, while nonparametric tests were used to analyse the data from the quantitative study. The research followed the ethics guidelines provided by the University of Newcastle Human Research Ethics Committee to ensure that the ethical practice in the study involving or impacting on humans was of the highest standard.

Data collection for the study was carried out between mid-September 2011 and mid-November 2011. The study was conducted in two private centres for children with disabilities in Amman, Jordan. The two centres provide services and programs predominantly to support individuals with disabilities (including children with ASD) and limited support to families. The next chapter reports the results of the quantitative and qualitative studies.
Chapter 4: Results

4.1 Overview

This chapter presents a description and discussion of the qualitative and quantitative analyses that were conducted on the sets of data collected for the purposes of the current project. This data was collected to understand the experience of parenting a child with ASD in Jordan and to determine whether the provision of an education program in Jordan for mothers of children with ASD increased mothers’ understanding of their child’s behaviour and improved the mothers’ coping skills and reduced their stress levels. The difference between mothers’ and fathers’ coping skills and stress was also examined. In addition, this study explored the fathers’ and professionals’ views of how disability is regarded in Jordanian culture.

The research was administered through three phases. The first phase involved in-depth interviews with 10 mothers who had a child with ASD, as well as the administration of the Parenting Stress Index (PSI) and Coping Strategy Indicator (CSI) with these mothers. The second phase involved the conduct of focus groups with 10 fathers (who were the marriage partners of the mothers from the first phase) and 10 professionals who worked in the same centres that the children attended. At the beginning of the fathers’ focus group meeting, fathers were also asked to answer the PSI and CSI scales. This phase also included the delivery of a parent education program. The final phase was a follow-up interview with the mothers after they had completed the parent education program, and the re-administration of the two scales with the mothers.

In order to answer the first research question: *How do Jordanian mothers experience parenting a child with ASD?*, content analysis was conducted on the pre-intervention interview data of the 10 mothers. The second research question: *Are there differences between mothers’ and fathers’ coping skills and stress?* was investigated using the Mann-Whitney U test to evaluate whether there was a statistically significant difference between the mothers and fathers scores on the PSI and CSI scales before the education program. In order to answer the third research question: *What effects does a training program have on the coping skills and stress levels of mothers of children with ASD?*, a Wilcoxon signed-ranks test was employed to compare the mothers’ pre-intervention and post-intervention scores on the PSI and CSI. The third question was also investigated using a content analysis of the
qualitative data obtained from the interviews that were conducted with the 10 mothers after
the completion of the education program. In order to answer the fourth research question:
*How is disability regarded in Jordanian culture by parents and professionals?*, a content
analysis was conducted on the mothers’ pre-intervention interviews and on the transcripts of
the discussion in the focus groups with the 10 fathers and 10 professionals. The following
section reports the results from the analyses of the qualitative and quantitative data pertaining
to each research question.

### 4.2 Q1: How do Jordanian mothers experience parenting a child with ASD?

A content analysis was conducted on the mothers’ pre-intervention interviews in order
to answer the first research question. Content analysis was chosen as it fitted most closely
with the aims of the research question. Content analysis is defined as the process of
identifying the main substantive points in an interview transcript and categorising them
(Liamputtong & Ezzy, 2005). The interviews were conducted in Arabic by the researcher (for
whom Arabic is a first language), and the content analysis was conducted on the Arabic
transcripts of the interviews. The first level of analysis was to establish the appropriate
categories that would best describe all the emerging themes. The second level involved
identifying the subthemes within each category. The content analysis identified four main
themes that best captured the phenomenon of Jordanian mothers’ experience of parenting a
child with ASD. For the credibility of the analysis, a second reader, a doctoral student who
was also a native speaker of Arabic and had experience in qualitative research, checked the
identified themes. The interviewer, as the first reader of transcripts and developer of the
codes, and the second reader discussed and resolved disagreements through consensus. The
four identified categories were *family functioning, parental stress, insufficient support,* and
*parental coping.* Only at this point were the categories and themes translated into English
from Arabic.

Table 4.1 summarises the categories and subthemes identified from the mothers pre-
intervention interviews. Three of these categories: family functioning, parental stress, and
insufficient support reflected the mothers’ experience of parenting a child with ASD. Parental
coping reflected the way in which the mothers’ reacted to these experiences.
### Table 4.1: Categories and subthemes in the mothers’ pre-intervention interviews

<table>
<thead>
<tr>
<th>Category</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.2.1 Family Functioning</td>
<td>4.2.1.1 Feelings of sadness, anxiety and isolation</td>
</tr>
<tr>
<td></td>
<td>4.2.1.2 Sibling relationships and reactions</td>
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<td>4.2.1.3 Father involvement</td>
</tr>
<tr>
<td>4.2.2 Mother Stress</td>
<td>4.2.2.1 Pessimism about the future</td>
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<tr>
<td></td>
<td>4.2.2.2 Fears about harm to their child</td>
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<tr>
<td></td>
<td>4.2.2.3 The child’s challenging behaviours</td>
</tr>
<tr>
<td>4.2.3 Insufficient Support</td>
<td>4.2.3.1 Social support</td>
</tr>
<tr>
<td></td>
<td>4.2.3.2 Financial support and resources</td>
</tr>
<tr>
<td>4.2.4 Parental coping</td>
<td>4.2.4.1 Proactive behaviours</td>
</tr>
<tr>
<td></td>
<td>4.2.4.2 Acceptance</td>
</tr>
</tbody>
</table>

#### 4.2.1 Family Functioning

As indicated in Table 4.1, family functioning was comprised of three subthemes. The first subtheme related to mothers’ feelings of sadness, anxiety and isolation and the second subtheme related to the child’s relationships with siblings and the siblings’ reactions to the diagnosis of ASD. The third subtheme related to father involvement.

##### 4.2.1.1 Feelings of Sadness, Anxiety and Isolation

Mothers spoke of having an ongoing sadness about their child starting from the child’s birth or at diagnosis of ASD. Eight of the mothers described the events around the birth of their child as “tragic” and talked about their gradual realisation of the implications the child’s disability had for their lives. They had feeling of sadness of what their son or daughter will never be able to do. Some examples of the mothers’ emotional reactions at the time of birth or diagnosis are presented below.

*The first time I knew that my child is autistic, I was very sad. (The mother started to cry).* (M1)

*The first time I knew about my child, my mental state was very bad and I was always crying.* (M2)

*When I knew that my child is autistic, I become unable of doing anything and just thought that this child has brought much sadness to us.* (M3)

As well as sadness, some mothers talked about the problems of having a child who looked ‘normal’ but who could not do what other children were doing. The reactions of
strangers or the difficulty in explaining the child’s condition to others caused feelings of anxiety and frustration in one mother.

“My son looks smart, he is more like a non-disabled child but no matter how he looked he is still a disabled child and this makes me feel bad and sad most the time. This situation makes me nervous and frustrated.” (M4)

The majority of mothers commented that they often hid their negative emotions (e.g., feeling upset, angry or anxious), instead of speaking out. The mothers’ emotional reactions were often compounded by family circumstances, particularly where there was a lack of understanding and support from family members.

“My mother-in-law who lives with me in the same house sometimes made comments about my child; these comments do not go with his situation. This made me upset but I cannot talk about my feeling and sadness. Therefore, my relationships have become very limited and I do not like to deal with other people.” (M1)

“The most difficulties we faced with our child is his behaviours, we cannot control it. This makes me anxious most of the time and the biggest problem is that I cannot talk to anyone about my child’s problem, so just I keep my feelings inside.” (M8)

### 4.2.1.2 Sibling Relationships and Reactions

This subtheme describes the reactions of the sibling toward the child with ASD and the relationships between the child with ASD and their siblings. The majority of mothers (n=7) said that their other children experienced mixed, and sometimes contradictory, feelings. The mothers reported that siblings often felt guilty or sad when their brother or sister was unable to participate in a particular activity or event. Some siblings felt embarrassed having a child in the family who was ill, disfigured, or disabled as it marked the family as “different”. Mothers spoke of the siblings’ shame. For example:

“My son is a loved one and trying to integrate to a certain degree with other children but he has a speech problem, so some children in our family do not accept him.” (M4)

“My son’s relationship with his brothers becomes tense because he breaks their toys so they do not like to deal with him.” (M7)

Although some siblings experienced negative feelings, others demonstrated less hostility and anger toward the impaired sibling than they did to their other brothers and sisters.
We do not leave him at home alone and everyone is trying to help him but in a planned way and we give him more attention because he is the last child in our family. (M6)

### 4.2.1.3 Father Involvement

Four mothers talked about their husbands’ involvement with their child with ASD.

One mother said:

*The problem is that the mother carries all the responsibility of her son at home my husband cannot do anything for our son. Sometimes I ask him to take care of our son while I am doing the housework but he did not want to assist.* (M5)

She goes on to say:

*The most important issue for my husband is working to earn money for our family needs.*

Another mother said:

*My husband does not accept the idea that my child is autistic. He does not allow me to follow any behavioural program with my son. For example, I'm trying to teach my son the proper way to eat as I have learned in the centre, but my husband is a big challenge and he always stops me from achieving that.* (M8)

Another mother said:

*My husband is dealing with my son as he is a sick child and he is trying to get him to achieve his desires without awareness if these desires are useful or harmful to him. He does not cooperate with me to change our child’s behaviour to something better.*

(M4)

In summary, the mothers showed feelings of sadness, anxiety and frustration of what their son or daughter will never be able to do, not just for the present but for the future. The impact on siblings and their reactions to the affected child was also an important issue for the mothers. Mothers expected their sons and daughters without a disability to provide help to them in caring for the child with ASD, but this rarely happened. Furthermore, fathers appeared to have little involvement with their child with ASD and typically did not help or support the mothers to manage the child’s behaviour. The mothers stated that the fathers’ involvement was usually limited to covering living expenses for the family.
4.2.2 Stress

The second category that emerged from the interview analysis was the stress that mothers experienced. The three subthemes were pessimism about the future, fears about harm to their child, and the child’s challenging behaviours.

4.2.2.1 Pessimism about the Future

In Jordan, employment and independent living services for children with disabilities have not been well developed. Hence, many mothers were concerned about the future and the child’s ability to take care of themself away from the family and were concerned about placement when the child finished school. One mother said:

*I am worried about my daughter after I die; there is no way the community system in our country can take care of her. Really I feel sad.* (M10)

4.2.2.2 Fears about Harm

The second subtheme identified by the majority of mothers (n=6) was the fear about harm to their child. This subtheme related to the possibility of other people, including the child’s teachers, harming their child.

*I am always worried about him and if someone would hurt him from the school or the centre* (M3).

4.2.2.3 The Child’s Challenging Behaviours

A third source of stress was the child’s challenging behaviours. All mothers (n=10) reported instances of violent and inappropriate behaviour of their children such as hurting themselves and others, breaking house objects, and searching visitors’ bags. These had a strong impact on the mothers’ daily lives.

*He appeared to become isolated and showed us a weird walking movement. More, his behaviour has become worse and he started to break anything around him. I know he has problems, but it is difficult to manage his behaviour.* (M9)

*My son is aggressive with others, especially if someone denied his request.* (M5)

In summary, mothers were stressed by their child’s behaviour, by concerns about their child’s future and by fears about harm to their child.
4.2.3 Insufficient Support

A lack of either social or financial support was the main subtheme identified in this category. The lack of support either from other family members or from services was mentioned by eight mothers.

4.2.3.1 Social Support

In relation to social support, a majority of the mothers (n=7) experienced isolation from friends and a loss of social contact after the birth or diagnosis of their child with ASD. Some mothers were also concerned that in cases where their child and family were included in social activities then it was because of feelings of sympathy rather than friendship. For example:

*Society does not accept my child and if someone does so it is just a kind of pity on me and my child.* (M8)

4.2.3.2 Financial Support

The mothers also spoke about the problems of finding financial support in Jordan. Seven mothers had tried without success to get help from different institutes, centres or governments. Some mothers (n=5) stated that they could not find any financial support and the cost of the special education centres was very high. One mother said:

*There is no support by the community and government especially for children with ASD. The government does not support them because they do not recognise ASD as an actual disability. The cost of treatment for those children in the special education centres is high and a family cannot provide adequate treatment for their children.* (M6)

However, some mothers (n=4) mentioned instances of support they had received from others and, when asked, most could think of a range of supports they would value. Some mothers identified several meaningful resources and supports for their children, such as schools, and mentioned the help they received from teachers.

*The most help I got was from other families that have the same or similar problem to me. I feel relaxed when I share feelings with my family or other families. I like to hear some advice from other people, especially centre teachers.* (M3)
4.2.4 Parental Coping

One of the aims of the interviews was to learn how mothers coped with family difficulties, and stress. Some mothers did not think that they did anything special; it was just a matter of having to do what they had to do. Others described various coping strategies. The two coping strategies that emerged from the interviews were proactive behaviours and acceptance.

4.2.4.1 Proactive Behaviours

*Proactive behaviours* describe the kinds of actions that mothers took in order to achieve a resolution to their difficulties. The proactive behaviours the mothers reported included seeking sources of social support, facing up to their problems, developing specific skills related to their child’s disability, helping other parents, and sharing feelings with other families. One mother said:

*I tried to overcome my problems for my child to help him overcome his problem. I tried to accept the situation as it is.* (M6)

4.2.4.2 Acceptance

*Acceptance* was another coping mechanism adopted by some mothers (*n=4*). These mothers would try to solve their problems through accepting the child and the impact of the child’s disability. The mothers tried to accept the situation as their destiny or fate and by comparing their situation with others and realising that they were better off.

*We accept our son as he is, we try do not leave him at home alone and everyone is trying to help him, he is our child and we’ll take care of him.* (M1)

In summary, mothers adapted to family difficulties through two coping strategies: proactive behaviours and acceptance. A common proactive coping behaviour among all of the Jordanian mothers was seeking sources of information to help understand their child’s diagnosis and facing up to their problems by developing specific skills related to their child’s disability. The most common coping skill reported by the Jordanian mothers in this study was problem solving by accepting the child and the impact of the child’s disability.
4.3 Q2: Are there differences between mothers’ and fathers’ coping skills and stress?

The total scores of the PSI and CSI scales for both mothers and fathers were computed to investigate the level of stress and coping in mothers and fathers prior to the education program. The mean total parenting stress and coping scores for both mothers and fathers are presented in Table 4.2 along with the results for each subscale of the PSI and CSI.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental distress (PD)</td>
<td>46.8 7.4</td>
<td>38.6 7.9</td>
</tr>
<tr>
<td>Parent-children dysfunctional PCDI</td>
<td>44.8 5.6</td>
<td>34.2 9.3</td>
</tr>
<tr>
<td>Difficult child (DC)</td>
<td>47.8 8.3</td>
<td>40.7 9.0</td>
</tr>
<tr>
<td>Parenting Stress Index scale (PSI) Total</td>
<td>139.4 18.8</td>
<td>113.5 24.6</td>
</tr>
<tr>
<td>CSI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem Solving (PS)</td>
<td>20.4 4.4</td>
<td>25.0 3.3</td>
</tr>
<tr>
<td>Seeking Social Support (SS)</td>
<td>18.2 5.2</td>
<td>23.5 3.1</td>
</tr>
<tr>
<td>Avoidance (A)</td>
<td>15.1 3.2</td>
<td>22.8 3.5</td>
</tr>
<tr>
<td>Coping Strategy Indicator (CSI)</td>
<td>53.7 12.0</td>
<td>71.3 8.6</td>
</tr>
</tbody>
</table>

The mean total PSI parenting stress scores for mothers and fathers were 139.4 and 113.5, respectively. The total stress score provides an overall indication of parenting stress that a parent is experiencing, with higher scores indicating greater stress. The totals for both mothers and fathers were above the 90th percentile. According to the manual, a parenting stress total raw score of \( \geq 90 \) indicates significant stress in the parent–child relationship and suggests that parents and their child should seek professional counselling (Abidin, 1995).

Table 4.2 also presents the results from the administration of the CSI to mothers and fathers. The CSI total score is a measure of how well the parent is coping with their situation with higher scores indicating better coping. As shown in Table 4.2, the mean total scores on the CSI for the mothers and fathers were 53.7 and 71.3, respectively.
Sometimes the distribution of variables is not normal or the samples are so small as to not represent a normal distribution. Given the small number of participants in this research, two nonparametric tests of group difference, the Mann-Whitney U-test and the Wilcoxon test, were used (Whitley & Ball, 2002). In order to evaluate whether there was a statistically significant difference between the mothers’ and fathers’ total scores on the PSI scale a Mann-Whitney U test was conducted. The test showed that there was a statistically significant difference between mothers’ and fathers’ PSI scores \(U = 21.5, p = 0.03\) with mothers having a higher ranking than fathers. This result indicates that the mothers reported significantly higher stress levels than the fathers.

The Mann-Whitney U test was also conducted to evaluate whether there was a statistically significant difference between the mothers’ and fathers’ total scores on the CSI scale. Again, the test showed that there was a statistically significant difference between mothers’ and fathers’ CSI scores \(U = 11.5, p = 0.02\) with mothers having a lower ranking, and a significantly lower coping level, than fathers.

In summary, the results showed that both parents of a child with ASD experienced a high level of stress, with mothers having a higher ranking and thus significantly higher stress, than fathers. The results also showed that the mothers of a child with ASD had a lower ranking, and a significantly lower coping capacity, than did fathers.

**4.4 Q3: What effects does a training program have on mothers of children with ASD including: Coping skills and Stress?**

Both the quantitative data collected from the CSI and the PSI scales for mothers and the qualitative data collected from the mothers post-interviews were used to answer this research question.

**4.4.1 Quantitative Data**

The total scores for the PSI and CSI scales for mothers were computed as the first phase of data analysis to investigate the level of stress and coping in mothers before and after the education program. The second phase of analysis involved using the Wilcoxon signed-ranks test for two repeated (or correlated) measures.

The PSI and CSI scores for mothers before and after the education program are presented in Table 4.3 for each subscale of the total scale score. The mean total mothers’ stress scores before and after the education programs were 139.4 and 98.2, respectively. Both
these totals were above the 90th percentile scores and, according to Abidin (1995), this indicated a high level of stress before the intervention and a moderate level of stress in mothers at the end of the intervention.

Table 4.3: Mean and standard deviation for PSI and CSI scales and subscales for mothers’ pre and post intervention

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mother (Pre)</th>
<th>Mother (Post)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>PSI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental distress (PD)</td>
<td>46.8</td>
<td>7.4</td>
</tr>
<tr>
<td>Parent-children dysfunctional PCDI</td>
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<tr>
<td>Difficult child (DC)</td>
<td>47.8</td>
<td>8.3</td>
</tr>
<tr>
<td>Parenting Stress Index scale (PSI) Total</td>
<td>139.4</td>
<td>18.8</td>
</tr>
<tr>
<td>CSI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem Solving (PS)</td>
<td>20.4</td>
<td>4.4</td>
</tr>
<tr>
<td>Seeking Social Support (SS)</td>
<td>18.2</td>
<td>5.2</td>
</tr>
<tr>
<td>Avoidance (A)</td>
<td>15.1</td>
<td>3.2</td>
</tr>
<tr>
<td>Coping Strategy Indicator (CSI)</td>
<td>53.7</td>
<td>12.0</td>
</tr>
</tbody>
</table>

Table 4.3 also presents the results of the pre and post CSI scale for mothers. The mean total scores for the pre and post CSI for mothers were 53.7 and 82.6, respectively.

The Wilcoxon signed-ranks test was used to check for differences in mothers’ stress levels before and after the education program. The test showed that following the education program the mothers reported a highly statistically significant reduction in stress levels as measured by the total score of the PSI ($Z = -2.803, p = 0.005$). A second Wilcoxon signed-ranks test showed that following the education program the mothers reported a statistically significant increase in coping skills as measured by the total scores on the CSI ($Z = -2.803, p = 0.005$).

4.4.2 Qualitative Data

Content analysis on the Arabic transcripts of the post-intervention interviews with the mothers was conducted in order to complement the findings from the quantitative data analysis and to provide a deeper understanding of the effects of the education program on the mothers’ stress levels and coping skills. As with the pre-intervention interviews, the first level of analysis was to establish the appropriate categories that best described the emerging
themes. For the credibility of the analysis, a second reader, a doctoral student who was also a native speaker of Arabic and had experience in qualitative research, checked the identified themes. The researcher, as the first reader of transcripts and developer of the codes, and the second reader discussed and resolved disagreements through consensus. Only at this point were the categories and themes translated into English from Arabic. The identified themes were closely related to the interview questions and produced three categories: (a) mothers’ satisfaction with the education program; (b) stress levels, and (c) coping skills.

4.4.2.1 Satisfaction with the Education Program

The content analysis revealed that all mothers expressed satisfaction with the education program and reported positive expectations about the implementation of the information and ideas they had learned about at the education program. For example, one mother said:

*I am very happy to participate in the program and I am very thankful for the valuable information I received from the program.* (M2)

The program aimed to provide the mothers with the skills and confidence to address their child’s challenging behaviour and some mothers reported that they felt encouraged and optimistic because the strategies they had learned about and were now using with their child appeared to be having a positive effect.

*I felt comfortable after the program and I tried to change my son’s behaviour … I tried to use some of what I learned to reduce these behaviours, and he seemed to start to respond.* (M5)

One mother commented that the program was beneficial because it had helped to correct her misunderstandings about ASD and also because she had the opportunity to talk to other mothers who understood her problems and concerns and gave her helpful advice and support.

*I felt happy to meet with other mothers, talking to them, hearing their experience and take some advice from them during the program sessions. I had some information before the program but not all was right, so the program corrected my information and educated me about children with ASD.* (M3)

Other mothers also described being impressed, when they first attended the program, that others (e.g., the researcher) cared, talked about, and planned for their child. In addition,
mothers \( n=9 \) were thankful because the strategies of the education program could be implemented at home without the need to travel long distances and to incur substantial costs. Most mothers \( n=7 \) indicated that a disadvantage of the program was its short duration.

### 4.4.2.2 Stress

The second category that emerged from the post-interview analysis was a reported decrease in the mothers’ stress levels after the education program. One mother identified that providing support and assistance for parents was just as important as the provision of services for the child with ASD.

*Parents of the child with ASD have high pressure and they need programs to help them. In my opinion, I think the importance of the education program is equal to the importance of the treatment of the child with ASD. A program such as this could help us to cope with our child and reduce the stress.* (M6)

Another mother said:

*Usually I do not accept any new information about my child, but now I feel less stressed and better in the sense that I want to deal with him (son) and with my family.* (M7)

### 4.4.2.3 Coping

The final category was mothers’ coping. The results of the post-intervention interviews showed that after the program the mothers had a better understanding of their children and many had developed specific skills which helped them cope with their problems. Some mothers reported being more accepting of their child and described how their feelings of shame were relieved.

One mother said:

*Through the program sessions and during the meetings with other mothers, I benefited a lot and then I tried to apply some of what I learned to my relationship with my child. I felt I got what I needed at the right time because I had a problem with the way to deliver any information to my child.* (M1)

Another mother stated that

*The program encouraged me to accept my child more.* (M7)
Some mothers \((n=7)\) reported that the program helped them to face up to their problems and also to develop skills related to their child’s disability. One mother said:

*The program helped me to learn some skills that helped me to overcome my problems.*  
(M6)

Overall, the results showed that the experience of mothers of a child with ASD in an education program was generally a positive journey for the majority of mothers in this study, and this was related to perceived improvements in their child’s behaviour following implementation of newly learned strategies and also improvements in their coping skills and stress levels. The education program increased the mothers’ knowledge and understanding about the behaviour and communication difficulties exhibited by children with ASD. This new awareness along with the support of other mothers in similar circumstances ultimately was associated with enhanced mothers’ coping and reduced stress levels.

### 4.5 Q4: How is disability regarded in Jordanian culture by parents and professionals

The aim of this question was to determine how disability was regarded in the Jordanian culture from the perspective of parents and professionals. Content analysis was conducted on the focus groups for fathers and professionals and on the mothers’ pre-intervention interview questions that related to this research aim. Content analysis was conducted on the Arabic transcripts of the focus groups and the mothers’ first interview. The content analysis identified five main themes that best captured the views of parents and professionals about the notion of disability in Jordanian culture. For the credibility of the analysis, a second reader, a doctoral student who was also a native speaker of Arabic and had experience in qualitative research, checked the themes that had been identified by the researcher. The researcher and the second reader discussed and resolved any disagreements about the themes through consensus. Only at this point were the categories and themes translated into English from Arabic. The five categories were: (a) *negative views of disability*; (b) *shame or isolation*; (c) *family difficulties*; (d) *lack of services and qualified staff* and; (e) *cost of services*.

#### 4.5.1 Negative Views of Disability

All of the parents and professionals believed that, in general, Jordanian society did not accept people with a disability and that few individual families accepted their own child with
a disability. The parents and professionals also stated that the situation was the same for children with ASD. Examples of fathers’ (F) comments were:

*Jordanian society has a negative view about children with ASD or children with special needs.* (F2)

*At the family level, some families accept the child with ASD and some do not.* (F4)

Examples of mothers’ (M) comments were:

*Society does not accept my child and if someone does so it is just a kind of pity on me and my child.* (M8)

One professional (P) took this view further with the conclusion that some families actually rejected and maybe even neglected their child with a disability.

*There are two sets of parents, one accepts their child with disability and those collaborate well with professionals. The other parents do not accept their children’s situation and sometimes they do not care about their child.* (P3)

### 4.5.2 Shame or Isolation

A small number of fathers and some professionals commented that one of the reasons that children with a disability are not generally accepted by society is because, in Jordan, having a child with a disability is regarded as shameful.

*Jordanian society does not accept a child with ASD and the child is seen as a kind of shame in the family.* (F1)

This sense of shame can sometimes cause families to stay at home and avoid mixing in society or to leave their child at home when the family goes out.

*Parents avoid taking their children with ASD to public places because there is a lack of social acceptance of their children.* (P5)

*Parents prefer to keep their child (with a disability) inside the house because the society rejects their child.* (P1)

Other professionals believed that a child or family could be isolated because there was a general lack of appropriate facilities for people with a disability.

*The child with ASD is isolated from society, the society does not provide any opportunities for families of a child with ASD to take them out to public places.* (P2)
4.5.3 Family Difficulties

Families with a child with ASD in Jordanian society faced many difficulties from fathers’ and professionals’ point of view. One difficulty was insufficient knowledge by fathers about how to deal with children with ASD.

*I am like any father of a child with ASD. The first time I knew about my child I became confused because I did not know anything about this disability and also there are no available sources of help or information, only searching the Internet.* (F1)

Some fathers mentioned that lack of knowledge and understanding about ASD was sometimes a cause of conflict between husbands and wives.

*There are many divorce cases after the family discover that their child has ASD because the husband does not understand his son’s situation and puts the blame on the mother.* (F2)

*Some mothers are trying to follow an appropriate treatment program for her child, but the husband is a big problem for her and her child because he does not understand and is not aware of his child’s condition.* (F7)

Some professionals noted that even if adequate information and support were available to families of children with ASD, the parents’ sense of pride and privacy might prevent them from allowing professionals to be involved in implementing interventions or making decisions affecting the families’ home lives.

*The parents do not have enough information about ASD and disability and we are trying to increase their awareness, but intervention is not easy and the parents do not allow anyone to interfere in their lives.* (P1)

Furthermore, some families expected that intervention and education services would provide an ‘instant cure’ and became impatient when there was not a dramatic and immediate improvement in their child’s development and behaviour.

*The problem is that the treatment of the child needs much time and needs great patience, and that treatment cannot done over a day or two. This is very hard to be understood by families of a child with ASD.* (P3)

4.5.4 Lack of Services and Qualified Staff

Another aspect that was particularly noted by fathers was the insufficient provision of services such as schools and centres for children with ASD.
Distribution of the treatment centres for ASD children is not fair; most of them are in the big cities and this makes it difficult for parents to find the appropriate place for their child. (F3)

The fathers also questioned whether there was an adequate number of staff in the specialized centres and whether these staff were sufficiently qualified to educate children with ASD.

There is an insufficient number of staff to help parents and children in the education centres. (P10)

There is a shortage of centres and staff in these centres that deal with the child with ASD. Even if these centres are new they do not have good knowledge or research about ASD. (F6)

In addition, one father was sceptical about the motives of the centres and suggested that profit was more important than the provision of qualified staff and effective services.

Most of the centres are commercial and are not qualified; they just need to collect some money and do not help the child. These centres are expensive. (F9)

4.5.5 Cost of Services

A final theme noted by fathers, mothers and professionals was the lack of financial support from the government for children with ASD and the poor economic situation for families with a child with ASD.

Parents do not have the ability to pay the costs of their child’s treatment. (F2)

The government could help in paying the medical tests for the child with ASD but it [the government] does not help in treatment for these children. (F3)

Parents could have the emotional ability to help their child but they don’t have the ability to carry the high cost of their child’s treatment in the special education centres. (P1)

There is no support by the community and government especially for children with ASD. The government does not support them because they do not recognise ASD as an actual disability. The cost of treatment for those children in the special education centres is high and a family cannot provide adequate treatment for their children. (M6)
In conclusion, all of the parents and professionals indicated that, in general, Jordanian society did not readily accept children with a disability and it appeared that even the families of a child with a disability had difficulty accepting their own child and integrating them into society. Parents and professionals also stated that the situation was the same for children with ASD. Parents were not satisfied with the support that was available for children with ASD in Jordan because it is very limited and expensive. In addition, the parents had concerns about the quality of the existing services and the qualifications and expertise of the staff employed at these centres. The professionals also shared the parents’ views about the insufficiency of appropriate services for children with ASD and were concerned about the lack of financial support from the government in light of the considerable expenses incurred by families seeking to access treatment and support for their child. Furthermore, most of the parents and professionals’ stated that many of the available centres provided services to the children without paying any attention to the needs of their families. In these centres, children are provided with educational, daily life activities and artistic works such as drawing and music, but parent education programs are not provided.
Chapter 5: Discussion

5.1 An Overview

This final chapter provides the significant findings of the research project while drawing conclusions on the basis of the research questions that were investigated. Accordingly, this chapter contains four major sections. In the first section, the research findings are discussed with reference to the literature review. In the second section the limitations and suggestions for future research are considered. In the third section the implications of the study are outlined and the final section presents the overall conclusions from the study.

5.2 Discussion of Research Findings

The current research aimed to understand the experience of parenting a child with ASD in Jordan and to determine whether the provision of an education program in Jordan for mothers of children with ASD increased mothers’ understanding of their child’s behaviour and improved the mothers’ coping skills and reduced their stress levels. The difference between mothers and fathers coping skills and stress was also examined. In addition, this study explored the fathers’ and professionals’ views of how disability is regarded in Jordanian culture.

As stated in section 3.2, a conceptual model (Figure 3.1) was used to guide the research questions, the research methodology and reporting of the data collection. Four research questions were developed to satisfy the current research aims and three types of data were collected to examine the research questions. The data sources were: pre and post-intervention interviews with 10 mothers of children with ASD; focus group interviews with the 10 mother’s husbands and with 10 professionals from the two special education centres from which the parents were recruited; and two questionnaires to measure the coping skills and stress levels of the mothers and fathers.

The first research question was: How do Jordanian mothers experience parenting a child with ASD? The results from the content analysis of the pre-intervention interview data of the 10 mothers of a child with ASD indicated that the mothers showed feelings of sadness, anxiety and frustration of what their son or daughter will never be able to do, not just for the present but for the future. The impact on siblings and their reactions to the affected child was
also an important issue for the mothers. Mothers expected their sons and daughters without a disability to provide help to them in caring for the child with ASD, but this rarely happened. Furthermore, according to the mothers’ testimony, their husbands appeared to have little involvement with their child with ASD. The mothers stated that the fathers’ involvement was usually limited to covering living expenses for the family.

The results also showed that Jordanian mothers were stressed by their child’s behaviour, by concerns about their child’s future and by fears about possible harm to their child. It appeared that many mothers experienced isolation from friends and a loss of social contact after the birth or diagnosis of their child with ASD. Some mothers were also concerned that in cases where their child and family were included in social activities then it was because of feelings of sympathy rather than friendship. The mothers also spoke about the problems of finding financial support in Jordan. They had tried without success to get help from different institutes, centres or the government. The mothers stated that they could not find any financial support and the cost of the special education centres was very high. However, some mothers mentioned instances of support they had received from others and, when asked, most could think of a range of supports they would value. Some mothers identified several meaningful resources and supports for their children, such as schools, and mentioned the help they received from teachers

A common proactive coping behaviour among all of the Jordanian mothers was seeking sources of information to help in understanding their child’s diagnosis and facing up to their problems by developing specific skills related to their child’s disability. The most common coping skill mentioned by the Jordanian mothers was accepting the child and the impact of the child’s disability. These results are consistent with the findings from a study by (Birkin, et al., 2004) that it would be helpful to supply parents with information about numerous educational methods, about available treatment options and about support services for their children with ASD. Furthermore, the results confirmed studies by Davis and Carter (2008), and Hassall et al. (2005) which provided evidence that high levels of stress are present in parents who are raising a child with ASD. The results of these studies showed that different characteristics of children’s behaviours were predictive of parenting stress.

The second research question was: Are there differences between mothers’ and fathers’ coping skills and stress? The data collected from the quantitative study using the Coping Strategy Indicator Scale (CSI) and the Parent Stress Index (PSI) scales were analysed. The Mann-Whitney U test showed that there was a statistically significant difference between
mothers’ and fathers’ PSI scores with mothers having a higher ranking, and significantly higher stress, than fathers. The Mann-Whitney test also showed that there was a statistically significant difference between mothers’ and fathers’ CSI scores with mothers having a lower ranking, and significantly less coping skills, than fathers.

The third research question was: *What effects does a training program have on mothers of children with ASD including: Coping skills and Stress?* The quantitative and qualitative data collected from the PSI and CSI scales for mothers and their post-intervention interviews were used to answer this research question. The Wilcoxon signed-ranks test was used to check for differences in mothers’ stress levels before and after the education program. The results indicated a high level of stress before the intervention and a moderate level of stress in mothers at the end of the intervention. For coping skills, the results showed that following the education program the mothers reported a statistically significant increase in coping levels. These results suggest the education program was beneficial in reducing the level of stress and increasing the level of coping in the group of 10 mothers.

The third research question was also examined using content analysis for the mothers’ post-intervention interviews. This phase was performed as a complement to and a confirmation of the quantitative data analysis. The results of this phase supported the quantitative results of the pre and post-intervention mothers’ CSI and PSI scales. Therefore, it is reasonable to say that the education program was associated with enhanced mothers’ understanding and may have led to an increase in their coping skills and a reduction in their level of stress. This productive change in mothers’ coping appeared to be related to receiving adequate information about autism from the program and exchanging experiences with other families in similar situations. Following the education program, the mothers had a better understanding of their child’s behaviour and developed specific skills related to addressing their child’s social and communication difficulties and problem behaviours. The results showed that the mothers reported an improved capacity to interact with their child because of their participation in the education program.

Similar results were found by Ergüner-Tekinalp and Akkök (2004). In examining the effects of a coping training program for parents of children with ASD, these researchers reported a significant difference between the control and experimental groups for post-test measures with the experimental group showing a higher use of social support as a coping strategy than the control group.
The fourth research question was: *How is disability regarded in Jordanian culture by parents and professionals?* The aim of this question was to determine how disability was regarded in Jordanian culture from the parents’ and professionals’ perspectives. Content analysis was conducted on the focus groups for fathers and professionals and on the mothers’ pre-intervention interviews. Content analysis of concepts in the focus groups and mothers pre-interviews indicated that, in general, Jordanian society did not readily accept children with a disability and furthermore, that few individual families accepted their own child with a disability. Parents and professionals also stated that the situation was the same for children with ASD. Parents were not satisfied with the support that was available for children with ASD in Jordan because it is very limited and expensive. In addition, the parents had concerns about the quality of the existing services and the qualifications and expertise of the staff employed at these centres. The professionals also shared the parents’ views about the insufficiency of appropriate services for children with ASD and were concerned about the lack of financial support from the government in light of the considerable expenses incurred by families seeking to access treatment and support for their child.

Most of the parents’ and professionals’ answers stated that many of the available centres provided services to the children without paying any attention to the needs of their families. In these centres, children are provided with educational, daily life activities and artistic works such as drawing and music, but parent education programs are not provided.

### 5.3 Limitations and Future Work

In the quantitative study, there were limitations arising from the sample size for this study. The sample size was relatively small because of time and resource constraints. The small sample size prevented the use of a range of more robust statistical analyses. Hence, future research should check the value of similar education programs with a larger sample. Moreover, the sample in this research covered only parents of children with ASD who were known to the special education centres. While this was done for convenience, the procedure may have excluded a more representative sample. Consequently, the generalisation of the results from this study can be made only to the parents of children with ASD registered at the special education centres. Making generalisations from these results to all Jordanian parents should be undertaken cautiously. Resource restrictions prevented the use of a control group in the study and so causality has not been demonstrated in this research project.
While the study tried to ensure that parents’ self-reports were valid, self-report is a data collection method with several limitations (Iacono, et al., 2009). For example, self-report may not be an accurate indication of reality. The researcher tried to reduce such limitations by collecting all the data herself and explaining to the parents how to complete the questionnaires.

A final limitation for this study lies in the nature of the short period of the education program for mothers of children with ASD and the lack of a long term follow up. This program was conducted by the researcher herself for just a short time, which raises the question about the sufficiency and soundness of the program. Parents of children with ASD would likely gain greater benefits from longer-term education and support programs.

Despite these limitations, the present exploratory study provides valuable insights into the experiences of Jordanian parents of children with ASD, which will assist in the development of parent education programs in Jordan. The acknowledged limitations of this study have led to suggestions for further research.

5.4 Implications

The results of this study have valuable implications for practice and intervention. According to the quantitative study results, these results confirmed the possibility of using the translated CSI and PSI scales from English to the Arabic language for measuring stress and coping skills in Jordanian mothers of children with ASD.

For children with ASD, the results of the qualitative analysis support the importance of parent education programs for those children. According to the conceptual model guiding this study which was developed from Bronfenbrenner’s ecological theory, strategies operating within the mesosystem to enhance family functioning will impact favourably on the microsystem of the child. Furthermore, Guralnick’s family systems framework (see Figure 2.1), indicates that the family and the broader social and environmental factors of the macrosystem are particularly crucial influences on the development of a child with a disability (Guralnick, 2011). Therefore, an education program for parents may help in improving the development of a child with ASD through enhancing the family’s knowledge, skills and confidence. These results are consistent with studies by Marshall and Mirenda (2002), and Boettcher, Koegel, McNerny, and Koegel (2003) which found these kinds of programs have the potential to produce considerable long-term alterations in behaviour resulting in enhanced everyday activities for children with ASD and their family. This
implies that if parents’ skills are increased, then a child’s disruptive behaviour problems may decrease. Furthermore, these programs may help in decreased sibling negative behaviours when they interact with the child with ASD in the family. This conclusion is consistent with a study by Boettcher et al. (2003) which found that education programs for parents had positive effects on children with ASD and their siblings, and elevated positive relationships between members of the family.

The analysis of mothers’ data in the present study demonstrated the importance of education programs for mothers of children with ASD in Jordan by increasing understanding of their child’s behaviour and improving their coping skills and reducing their stress levels. Mothers felt satisfied with the education program they had received. This research has provided insight from 10 mothers whose experience with their child’s behaviour may not be typical of the larger population of Jordanian mothers of a child with ASD. However, a comparison of these findings with those from related studies (Aliwah, 1999; Asaod, 2008; Birkin, et al., 2008; Erg¨uner-Tekinalp & Akk¨ok2, 2004; Hardy, 1999; Roberts, et al., 1991; Shields, 2001; South Eastern Sydney & Illawarra Area, 2005) suggest that the strategies of education programs for mothers of children with ASD could be implemented in local education services or in the family home. This would help parents support their children without the need to travel long distances and to incur substantial costs.

A further implication of this research is that the findings suggested that there is a need for a broader understanding of disability within Jordanian culture, the provision of more specialist services and the implementation of strategies to create greater acceptance and inclusion of children and adults with a disability. This information can be helpful for government officials responsible for support services, and for professionals who work with children with a disability and their families.

5.5 Conclusions

The purpose of the present study was to understand the experience of parenting a child with ASD in Jordan and to determine whether the provision of an education program in Jordan for mothers of children with ASD increased mothers’ understanding of their child’s behaviour and improved the mothers’ coping skills and reduced their stress. The results found that the experience of an education program was generally a positive journey for the majority of mothers in this study, and this was for many, related to their child’s behavioural progress and improvements in the mothers’ coping skills and stress levels. The reasons for
involving mothers in the education program in this study were because of the limited number of special education centres and resources in Jordan and the limited capacity of the existing centres to be able to meet the mothers’ needs. Only mothers, not fathers, were included in the education program because, in Jordan, mothers carry the major burden of child-raising during the early years and because most fathers work during the day when the program was conducted. Mothers in this current study reported that the education program was beneficial in reducing their stress, increasing their coping skills, and improving their interactions with their child. This seemed to be because the mothers had greater knowledge about ASD, a better understanding of their own child and they developed specific skills related to facing up to their problems. The new coping skills most frequently mentioned by the Jordanian mothers was learning how to accept their child and the impact of the child’s disability, problem solving, helping other parents, and sharing feelings with other families.

Furthermore, the findings showed that according to the small group of parents and professionals involved in this study Jordanian society does not appear to accept children with disability in general and that few individual families accept even their own child with ASD. Parents were not satisfied with the social and financial support from the Jordanian society and government. One recommendation regarding these findings, is that the Jordanian government should develop and fund specialist educational and support services to provide a range of supports for children with disability and their families. Governments should also give attention to positive changes to policy, legislation and service practices towards raising and promoting social awareness and acceptance of people with disability. These recommendations match Guralnick’s framework (Guralnick, 2011) of seeing the availability of relevant material resources (e.g., social and financial support) related to the enhancement of family patterns of engagement and interaction. The findings from the present study suggest that this kind of family support is an investment that will help promote optimal development in young children with a disability, so that as adults they will be better equipped to live and work independently and contribute both socially and economically to Jordanian society.
References


RESEARCH APPENDICES
Appendix 1: Information Statements

Appendix 1.1: Information Statements for Centres

Information Statement for Centres
Research Project:
Education program for mothers of children with Autism Spectrum Disorder in Jordan

17-8-2011

Dear Sir/Madam,

Staff and parents at your centre are invited to participate in the research project identified above which is being conducted by Mrs Amany Al-Khalaf, as part of her Master of Philosophy program under the supervision of Associate Professor Ian Dempsey and Dr. Kerry Dally from the Centre for Special Education and Disability Studies, University of Newcastle, Australia.

Why is the research being done?

The present study aims to understand the experience of parenting a child with Autism Spectrum Disorder (ASD) in Jordan. The study will also implement a brief education program for mothers of children with ASD in order to investigate the effectiveness of the program in increasing mothers’ understanding of ASD and their child and whether it improves mother’s confidence and competence. The program will be free and offered locally so that the mothers will not need to pay or travel long distances. The research will also investigate the opinions of fathers of children with ASD and the opinions of professionals who work with children with ASD.

Who can participate in the research?

Both parents (i.e. mothers and their partners) of a child with ASD, as well as professionals who support children with ASD can participate in this research. For parents of a preschool age child with ASD, the number of participants will be limited to 10 mothers and their partners. In a case where more than 10 mothers and their partners agree to participate, the participants will be randomly selected. Those not selected will be thanked for their interest and will be provided with written information on ASD. For professionals, the number of participants will be limited to 10 professionals who work at the Centre. If more than 10 professionals agree to participate, the professional participants will be randomly selected and those not selected will be thanked for their interest.
What choice do you have?

Participation in this research is entirely the participants’ choice. Only those people who give their informed consent will be included in the project. Whether or not participants decide to participate, their decision will not disadvantage them or their child. If participants do decide to participate they may withdraw from the project at any time without giving a reason.

What would you be asked to do?

If you agree to allow this research to be conducted with staff and parents from your centre, you will be asked to distribute an invitation and information letter and consent forms to the parents of children with ASD and the professionals who work with children with ASD at your Centre. Those parents and professionals who consent to participate in the study will be asked to do the following:

1. Mothers will be interviewed for up to 60 minutes about their understanding and experience of disability, and they will complete three questionnaires about their parenting confidence and competence.
2. Mothers will take part in an education program running for two one-hour sessions per week for four weeks. The education program will comprise eight-sessions developed and delivered by the researcher (Amany Al-Khalaf). Mrs Al-Khalaf is a psychologist and she has had previous experience as a counsellor at public schools in Jordan. Furthermore, the researcher has recently completed training in conducting sessions for parents of children with additional needs.
3. The education program framework will include a series of presentations by the researcher covering topics such as information about ASD and treatment approaches, addressing communication problems, encouraging social interactions and making friends, developing play skills and managing repetitive and difficult behaviour. Each session will also include time for discussion, and sharing of ideas and experiences among the participants. If, for any reason a mother cannot attend a session, the researcher will provide her with information about the absent session.
4. Mothers will be involved in a second interview after the education program for about 60 minutes. The interviews aim to investigate how mothers responded to the education program and whether the program led to improved mothers’ understanding of their children’s behaviours.
5. Fathers will be involved in a focus for up to 60 minutes. The aim of this focus group is to discuss how disability is regarded in Jordanian culture from a parent’s perspective, and fathers will complete two questionnaires about their parenting confidence and competence.
6. Professionals will be involved in a focus group for up to 60 minutes. The aim of this focus group is to discuss how disability is regarded in Jordanian culture from a professional viewpoint.

If convenient, Mrs Al-Khalaf would like to complete the interviews, focus groups and education program at your Centre.

What are the risks and benefits of participating?

There are minimal risks associated with the participation in this study. However, participation will provide you with information about ASD that may assist them. The results from the study will be used to understand the experience of parenting a child with ASD in Jordan and to check whether an education program is beneficial for Jordanian parents of children with ASD. If it is the case, that any participants become distressed or feel uncomfortable with the interview/questionnaire, the interview will be stopped immediately. The researcher will allow the participant to take a break and provide
support as needed until they recover. The participant will then be given a choice of either resuming or terminating the interview. If the participant remains overly distressed, they will be offered further counselling by the researcher or referred for other appropriate support.

How will your privacy be protected?

The name and location of your Centre and the identity of participants will not be used in reports of this research. All research data will be securely stored for seven years, before it is destroyed, and will only be accessed by the researcher and her supervisors. Parents and professionals can choose to withdraw their data, if they wish. The audio tapes will be destroyed once they have been transcribed.

How will the information collected be used?

Results of the study will be reported in a thesis to be submitted for the degree of Master of Philosophy, by Mrs Amany Al-Khalaf, in the School of Education at the University of Newcastle. Moreover, it will be used in research papers for presentation at conferences and in journals. Each Centre will be given a copy of a summary report of the results.

What do you need to do to participate?

Participants need to read the Information Statement and be sure they understand its contents before they agree to participate. If there is anything they do not understand, or they have questions, please contact Amany Al-Khalaf by e-mail at amany.al-khalaf@uon.edu.au or by phone at +962777314047.

If participants would like to participate in this study, they need to complete the attached Consent Form, and return it to Mrs Al Khalaf in the reply paid envelope. If you are in agreement, the interviews, focus groups and the education program will be conducted at a mutually convenient time in a private room at your centre.

Yours sincerely,

A/Prof. Ian Dempsey  Dr. Kerry Dally  Mrs Amany Al-Khalaf

Supervisor  Supervisor  MPhil student

Complaints about this research

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2011-0215. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, you may contact the researcher, Mrs Amany Al-Khalaf,(+962777314047 or +61449785278) or A/Prof. Ian Dempsey, +61 2 4921 6282, or Dr. Mohammad Al-Safasfeh (Lecturer at Department of Special Education/Mutah University/Jordan), dr.mohamad@hotmail.com as a local contact for complaints, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive Callaghan NSW 2308, telephone +61+ 249216333, email Human-Ethics@newcastle.edu.au
Information Statement for Parents for the Research Project:
Education program for mothers of children
with Autism Spectrum Disorder in Jordan

17-8-2011

Dear Parents,

You are invited to participate in the research project identified above which is being conducted by Mrs Amany Al-Khalaf, as part of her Master of Philosophy program under the supervision of Associate Professor Ian Dempsey and Dr. Kerry Dally from the Centre for Special Education and Disability Studies, University of Newcastle, Australia.

Why is the research being done?

The study aims to understand the experience of parenting a child with Autism Spectrum Disorder (ASD) in Jordan. The study will also implement a brief education program for mothers of children with ASD in order to investigate the effectiveness of the program in increasing mothers’ understanding of ASD and their child and whether it improves mother’s confidence and competence. The program will be free and offered locally so that the mothers will not need to pay or travel long distances. The research will also investigate the opinions of fathers of children with ASD and the opinions of professionals who work with children with ASD.

Who can participate in the research?

Both parents (i.e. mothers and their partners) of a preschool age child with ASD. The researcher has asked your Centre Directors to send you an invitation and information statement and consent letters to participate in our research project. The participants will be parents of a preschool age child with ASD. The number of participants will be limited to 10 mothers and their partners. In a case where more than 10 mothers and their partners agree to participate, the participants will be randomly selected. Those not selected will be thanked for their interest and will be provided with written information on ASD.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will
not disadvantage you or your child. If you do decide to participate you may withdraw from the project at any time without giving a reason.

What would you be asked to do?

If both you and your partner agree to participate in the study, you will be asked to do the following:

1. Mothers will be interviewed for up to 60 minutes about their understanding and experience of disability, and they will complete three questionnaires about their parenting confidence and competence.
2. Mothers will take part in an education program running for two one-hour sessions per week for four weeks. The education program will comprise eight sessions developed and delivered by the researcher (Amany Al-Khalaf). Mrs Al-Khalaf is a psychologist and she has had previous experience as a counsellor at public schools in Jordan. Furthermore, the researcher has recently completed training in conducting sessions for parents of children with additional needs.
3. The education program framework will include a series of presentations by the researcher covering topics such as information about ASD and treatment approaches, addressing communication problems, encouraging social interactions and making friends, developing play skills and managing repetitive and difficult behaviour. Each session will also include time for discussion and sharing of ideas and experiences among the participants. If, for any reason a mother cannot attend a session, the researcher will provide her with information about the absent session.
4. Mothers will be involved in a second interview after the education program for about 60 minutes. The interviews aim to investigate how mothers responded to the education program and whether the program led to improved mothers’ understanding of their children’s behaviours.
5. Fathers will be involved in a focus for up to 60 minutes. The aim of this focus group is to discuss how disability is regarded in Jordanian culture from a parent’s perception, and they will complete three questionnaires about their parenting confidence and competence.

What are the risks and benefits of participating?

There are minimal risks associated with your participation in this study. However, participation will provide you with information about ASD that may assist you. The results from the study will be used to understand the experience of parenting a child with ASD in Jordan and to check whether an education program is beneficial for Jordanian parents of children with ASD. If it is the case, that you become distressed or feel uncomfortable with the interview/questionnaire, the interview will be stopped immediately. You will be able to take a break and will be provided with support by the researcher until you recover. You will then have a choice of either resuming or terminating the interview. If you continue to feel overly distressed, you will be offered further counselling by the researcher or referred for other appropriate support.

How will your privacy be protected?

Although a reference number will be provided to every participant to allow mothers’ and fathers’ information to be compared, this reference number will be kept separate to participants’ identity, and both the reference number and personal identifiers will be kept separately in a secure location and will not be shared with others. All research data will be securely stored for seven years, before it
is destroyed, and will only be accessed by the researcher and her supervisors. For interview data, you will be able to review the recording and transcripts to edit or erase your contribution. You can also withdraw your questionnaire data, if you want. The audio tapes will be destroyed once they have been transcribed.

**How will the information collected be used?**

Results of the study will be reported in a thesis to be submitted for the degree of Master of Philosophy, by Mrs Amany Al-Khalaf, in the School of Education at the University of Newcastle. Moreover, it will be used in research papers for presentation at conferences and in journals. Each Centre will be given a copy of a summary report of the results, and you can receive this report if you provide your email address and tick the request box on the consent form.

**What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you agree to participate. If there is anything you do not understand, or you have questions, please contact Amany Al-Khalaf by e-mail at amany.al-khalaf@uon.edu.au or by phone at +962777314047. If you would like to participate in this study, please complete the attached Consent Form, and return it to the collection box which has been placed in a discrete location at the Centre your child attends. Amany will then contact you by phone to arrange a time convenient to you for an interview prior to the education program. The interview and education program will be conducted at your child’s centre.

Yours sincerely,

A/Prof. Ian Dempsey
Supervisor

Dr. Kerry Dally
Supervisor

Mrs Amany Al-Khalaf
MPhil student

**Complaints about this research**

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2011-0215. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, you may contact the researcher, Mrs Amany Al-Khalaf, (+962777314047 or +61449785278) or A/Prof. Ian Dempsey, +61 2 4921 6282, or Dr. Mohammad Al-Safasfeh (lecturer at the Department of Special Education/Mutah University/Jordan), dr.mohamad@hotmail.com as a local contact for complaints, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive Callaghan NSW 2308, telephone +61+ 249216333, email Human-Ethics@newcastle.edu.au.
Appendix 1.3: Information Statements for Professionals

Information Statement for Professionals for the Research Project:
Education program for mothers of children
with Autism Spectrum Disorder in Jordan

17-8-2011

Dear Professional,

You are invited to participate in the research project identified above which is being conducted by Mrs Amany Al-Khalaf, as part of her Master of Philosophy program under the supervision of Associate Professor Ian Dempsey and Dr. Kerry Dally from the Centre for Special Education and Disability Studies, University of Newcastle, Australia.

Why is the research being done?

The study aims to understand the experience of parenting a child with Autism Spectrum Disorder (ASD) in Jordan. The study will also implement a brief education program for mothers of children with ASD in order to investigate the effectiveness of the program in increasing mothers’ understanding of ASD and their child and whether it improves mother’s confidence and competence. The program will be free and offered locally so that the mothers will not need to pay or travel long distances. The research will also investigate the opinions of fathers of children with ASD and the opinions of professionals who work with children with ASD.

Who can participate in the research?

Professionals who support children with ASD.

The researcher has asked your Centre Directors to send you an invitation and information statement and consent letters to participate in our research project. The participants will be professionals who support children of preschool age with ASD. The number of participants will be limited to 10 professionals who work at the Centre. If more than 10 professionals agree to participate, the professional participants will be randomly selected and those not selected will be thanked for their interest.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate you may withdraw from the project at any time without giving a reason.

What would you be asked to do?

If you agree to participate in the study, you will be asked to participate in a focus group with other professionals for up to 60 minutes. The aim of this focus group is to discuss how disability is regarded in Jordanian culture from a professional view point.

What are the risks and benefits of participating?
There are no risks associated with your participation in this study. However, participation will provide you with information about ASD that may assist you. The results from the study will be used to understand the experience of parenting a child with ASD in Jordan and to check whether an education program is beneficial for Jordanian parents of children with ASD.

**How will your privacy be protected?**

Although the focus group discussion will be audio recorded, the recording will be kept in a secure location and will not be shared with others. All research data will be securely stored for seven years, before it is destroyed, and will only be accessed by the researcher and her supervisors. You will be able to review the recording and transcripts to edit or erase your contribution, if you wish. The audio tapes will be destroyed once they have been transcribed.

**How will the information collected be used?**

Results of the study will be reported in a thesis to be submitted for the degree of Master of Philosophy, by Mrs Amany Al-Khalaf, in the School of Education at the University of Newcastle. Moreover, it will be used in research papers for presentation at conferences and in journals. Each Special Education Centre will be given a copy of a summary report of the results, and you can receive this report if you provide your email address and tick the request box on the consent form.

**What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you agree to participate. If there is anything you do not understand, or you have questions, please contact Amany Al-Khalaf by e-mail at amany.al-khalaf@uon.edu.au or by phone at +962777314047.

If you would like to participate in this study, please complete the attached Consent Form, and return it to the collection box which has been placed in a discrete location at the Centre where you work. Amany will then contact you by phone to make arrangements for the focus group. The focus group will be conducted at your centre.

Yours sincerely,

A/Prof. Ian Dempsey  
Dr. Kerry Dally  
Mrs Amany Al-Khalaf  

Supervisor  
Supervisor  
MPhil student  

**Complaints about this research**

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2011-0215.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, you may contact the researcher, Mrs Amany Al-Khalaf, (+962777314047 or +61449785278) or A/Prof. Ian Dempsey, +61 2 4921 6282, or Dr. Mohammad Al-Safasfeh (Lecturer at the Department of Special Education/Mutah University/Jordan), dr.mohamad@hotmail.com as a local contact for complaints, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive Callaghan NSW 2308, telephone +61+ 249216333, email Human-Ethics@newcastle.edu.au
Appendix 2: Consent Forms

Appendix 2.1: Consent Forms for Centres Directors

Consent Form

Associate Professor Ian Dempsey
School of Education
University of Newcastle
University Drive
Callaghan NSW 2308 Australia

Consent Form for Centre Directors for the Research Project:
Education program for mothers of children with
Autism Spectrum Disorder in Jordan
17-8-2011

I agree that my centre can participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand my centre can withdraw from the project at any time and we do not have to give any reason for withdrawing.

I understand that I am consenting to distributing information letters and consent forms to the mothers and fathers of children with Autism Spectrum Disorder (ASD), and to the professionals who work with (ASD), in my Centre.

I understand that my Centre will not be identified in any reports of this research.

I have had the opportunity to have questions answered to my satisfaction.

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<th>Centre Director’s name (please print):</th>
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Appendix 2.2: Consent Forms for both Mothers and Fathers

Consent Form

Consent Form for both mothers and fathers for the Research Project:
Education program for mothers of children with Autism Spectrum Disorder in Jordan
15-8-2011

We agree to participate in the above research project and give our consent freely.

Consenting means that both I and my partner agree to participate

We understand that the project will be conducted as described in the Information Statement, a copy of which we have retained.

We understand we can withdraw from the project at any time and do not have to give any reason for withdrawing.

For mothers, I understand that I am consenting to:

- participating in a pre and a post interview and having it recorded
- making myself available to complete a 4 week parent education program

For fathers, I understand that I am consenting to:

- participating in a focus group and having it recorded

We are aware we will be able to review, edit or erase the transcribed interviews.

We understand that our personal information will remain confidential to the researchers

We have had the opportunity to have questions answered to our satisfaction.

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<tr>
<th>Mother’s name (please print):</th>
<th>Father’s name (please print):</th>
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<td>Summary report of the results: Yes ☐ No ☐</td>
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Appendix 2.3: Consent Forms for Professionals

Consent Form

Associate Professor Ian Dempsey
School of Education
University of Newcastle
University Drive
Callaghan NSW 2308 Australia

Consent Form for professionals for the Research Project:
Education program for mothers of children with
Autism Spectrum Disorder in Jordan
15-8-2011

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I understand that I am consenting to participating in a focus group and having it recorded.

I am aware I will be able to review, edit or erase the transcribed interviews.

I understand that my personal information will remain confidential to the researchers

I have had the opportunity to have questions answered to my satisfaction.

| Professional’s name (please print): |
| Phone: |
| Email: |
| Signature: |
| Date: |
| Summary report of the results: Yes☐ No☐ |
Appendix 3: The Coping Strategy Indicator Scale (CSI)
Items

(Amirkhan, 1990)

*** How often in the past six months have you:

(1) Not at all, (2) a little, (3) a lot

1. Described your feelings to a friend. (SS)
2. Rearranged things so your problem could be solved. (PS)
3. Thought of many ideas before deciding what to do. (PS)
4. Tried to distract yourself from the problem. (A)
5. Accepted sympathy and understanding from someone. (SS)
6. Did all you could to keep others from seeing how bad things really were? (A)
7. Talked to people about the situation because talking about it made you feel better. (SS)
8. Set some goals for yourself to deal with the situation. (PS)
9. Weighed up your options carefully. (PS)
10. Daydreamed about better times. (A)
11. Tried different ways to solve the problem until you found one that worked. (PS)
12. Talked about fears and worries to a relative or friend. (SS)
13. Spent more time than usual alone. (A)
14. Told people about the situation because talking about it helped you come up with solutions. (SS)
15. Thought about what needs to be done to straighten things up. (PS)
16. Turned your full attention to solving the problem. (PS)
17. Formed a plan in your mind. (PS)
18. Watched television more than usual. (A)
19. Went to someone friend or professional to help you feel better. (SS)
20. Stood firm and fought for what you wanted in the situation. (PS)
21. Avoided being with people in general. (A)
22. Buried yourself in a hobby or sports activity to avoid the problem. (A)
23. Went to a friend to help you feel better about the problem. (SS)
24. Went to a friend for advice about how to change the situation. (SS)
25. Accepted sympathy and understanding from friends who had the same problem. (SS)
26. Slept more than usual. (A)
27. Fantasized about how things could have been different. (A)
28. Identified with characters in movies or novels. (A)
29. Tried to solve the problem. (PS)
30. Wished that people would just leave you alone. (A)
31. Accepted help from a friend or relative. (SS)
32. Sought reassurance from those who know you best. (SS)
33. Tried to carefully plan a course of action rather than acting on impulse. (PS)

SS = Social Support, PS = Problem Solving, A = Avoidance

All items on the Avoidance subscale were reverse scored so that high scores indicate better coping mechanisms.
Appendix 4: The Parent Stress Index (PSI) Items

(Abidin, 1995)

(1) Strongly disagree   (2) disagree   (3) not sure   (6) agree   (7) strongly agree

**Parenting distress**

1. I often have the feeling I cannot handle things very well
2. I find myself giving up more to meet my children’s needs
3. I feel trapped by my responsibilities as a parent
4. I have been unable to do new and different things
5. I feel that I am almost never able to do things that I like to do
6. I am unhappy with the last purchase of clothing
7. There are quite a few things that bother me about my life
8. Having a child has caused more problems in my relationship with my spouse
9. I feel alone and without friends
10. When I go to a party, I usually expect not to enjoy myself
11. I am not as interested in people as I used to be
12. I don’t enjoy things as I used to

**Dysfunctional interaction**

13. My child rarely does things for me that make me feel good
14. Most times I feel that my child does not like me
15. My child smiles at me much less than I expected
16. I get the feeling that my efforts are not appreciated very much
17. When playing, my child doesn’t often giggle or laugh
18. My child doesn’t seem to learn as quickly as most children
19. My child doesn’t seem to smile as much as most children
20. My child is not able to do as much as I expected
21. It is very hard for my child to get used to new things
22. I feel that I am not very good at being a parent
23. I expected to have closer and warmer feelings for my child than I do and this bothers me
24. My child does things that bother me just to be mean
**Difficult child**

25. My child seems to cry or fuss more often than most children
26. My child generally wakes up in a bad mood
27. I feel that my child is very moody and easily upset
28. My child does a few things which bother me a great deal
29. My child reacts strongly when something happens
30. My child gets upset easily over the smallest thing
31. My child’s sleeping or eating was much harder to establish
32. Getting my child to do something is much harder
33. Count the number of things which your child does that bother you
34. There are some things that my child does that really bother me a lot
35. My child turned out to be more of a problem than I had expected
36. My child makes more demands on me than most children
Appendix 5: The Intervention Interviews Questions

Appendix 5.1: The Pre-intervention Interviews Questions

1. What is your child age?
2. When the ASD child has been diagnosed?
3. How did you first know there was something different about your child?
4. How was the ASD child diagnosis?
5. Is the child a beneficiary of the special education centre?
6. How did you response when you first time recognised that your child is ASD child?
7. What kind of thing do you find most difficult with your child?
8. How does the culture of society accept a child with ASD?
9. Do you have relationships with other families having a child with ASD?
10. What kind of relationship do you have with your child with ASD?
11. Are other family members helping you with your child with ASD?
12. What are the behaviours that you still notice on your child with ASD?
13. Does your child has a particular custom or habit?
14. Does your child has trouble with sleeping, eating or personal cleanliness?
15. In relation to society, how your child's relationship with the society?
16. Is there any assistance from the society and the government to your child?
17. What kind of activity makes your child happy?
18. What are the most things upset you child?
19. When you go to the market or shopping centres, do you take your child with ASD with you?
20. Do you see that you are delinquent with your child?
21. What kinds of family activities do you have with your child?
22. Do you feel that you are able to control your child behaviour?
Appendix 5.2: The Post-intervention Interviews

Questions

1. How do you feel after the education program?
2. What other/different sessions were needed?
3. How has your knowledge about ASD changed after the program?
4. Tell me about any changes in yourself after the program?
5. Tell me about any changes in your child’s behaviour after the program?
6. How is your child going with this change?
7. What are the positives and negatives of the program?
Appendix 6: Focus Groups (Fathers, Professionals) Questions

Appendix 6.1: Focus Group Questions for Fathers

1. How do Jordanian cultures accept a child with disability?
2. How do Jordanian cultures accept your child with ASD?
3. What is the most difficult aspect in Jordanian culture that you face as the father of a child with ASD?
4. What kind of support do you have to help your child with ASD?
5. Are you satisfied with this support?

Appendix 6.2: Focus Group Questions for Professionals

1. How do the cultures of society accept a child with disability?
2. What is most difficult aspect in Jordanian culture facing the family of a child with disability?
3. What kind of support do the families of children with ASD have to help their child with ASD?
نموذج موافقة لكل من الأمهات والآباء على المشاركة في هذا البحث:

برنامج تثقيفي لامهات الأطفال المصابين بالتوحد في الأردن

توافق على المشاركة في هذا البحث وقد قدمنا موافقتنا بمحة ارتدنا.

الموافقة تعني ان وزوجي سوف نشارك في هذا المشروع.

نتفهم أن المشروع سوف ينجز كما هو مبين في بيان المعلومات، والتي سماحت بنشرته عنده.

نتفهم أنه يمكننا أن نسحب من المشروع في أي وقت دون اعطاء أي سبب لذلك.

الامهات، افهم أنني أوافق على:

المشاركة في المقابلة قبل و بعد البرنامج وسيتم تسجيلها.

• استعداد للمشاركة في برنامج تعليمي لمدة أربعة أسابيع.

الأباء، افهم أنني أوافق على:

المشاركة في المجموعة الرئيسية للأباء وسيتم تسجيلها.

ندرك اننا سنكون قادرين على مراجعة وتعديل ومحفو المقابلات المنسوبة.

ندرك ان المعلومات ستبقى سرية للباحث.

كانت لدينا الفرصة لطرح الأسئلة والحصول على الإجابات المرجعية لنا.

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ملخص تقرير نتائج البحث: نعم لا
Appendix 7.2: The Coping Strategy Indicator Scale (CSI) Items (Arabic Version)

مقياس مواجهة التحديات

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<td><strong>5.</strong> قلت التعاطف والتفهم من شخص ما</td>
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<td><strong>6.</strong> عملت ما في وسعك لدعم الآخرين من رؤية الأشياء السببية</td>
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<td><strong>7.</strong> تحدثت إلى الناس حول الوضع لأن الحديث عن هذا الأمر جعلك تشعر بتحسن</td>
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<td><strong>9.</strong> قارنت بين حياتك بعنيدة</td>
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<td><strong>10.</strong> حملت باليقظة عن طرفي أفضل</td>
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<td><strong>12.</strong> تحدثت عن متاعبك وهمومك لصديق أو صديق</td>
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<td><strong>13.</strong> قضيت وقتًا أطول من المعتاد وحداً</td>
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<td><strong>24.</strong> ذهبت إلى أحد الأصدقاء للحصول على المشورة حول كيفية تغيير هذا الوضع</td>
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<td><strong>27.</strong> استبدين كلمة توهمنك بكلمة تخلért</td>
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<td><strong>29.</strong> حاولت حل المشكلة</td>
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<td>15.</td>
<td>طفلي يتساءل في وجهي أقل بكثير مما كنت أتوقع.</td>
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<tr>
<td>16.</td>
<td>لدي الطفلك القعيدي ليست مهتمة كثير جدا.</td>
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<td>17.</td>
<td>عندما يلبب طفلي غالباً لا يهني أو يضحك.</td>
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<td>18.</td>
<td>طفلي لا يبدو أنه يعذر بسرعة.</td>
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<td>19.</td>
<td>لا يلبس طفلي بالطفل الكاف.</td>
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<td>20.</td>
<td>طفلي غير قادر على فعل الأشياء كما كنت أتوقع.</td>
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<td>21.</td>
<td>من الصعب للغاية لطفلي الاعتناء بالأشياء الجديدة.</td>
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<td>22.</td>
<td>أشعر أنني أستمتع حداً كفاً.</td>
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<td>23.</td>
<td>كنت أتوقع أن يكون أقدر قرباً وم有意اً أكثر دفناً تجاه طفلي، وهذا يزعجني.</td>
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<td>24.</td>
<td>طفلي يفعل أشياء لازعاجي لمجرد أن يكون لدي.</td>
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<td>25.</td>
<td>طفلي يكبي ويبدد احتجاجاً أكثر بكثير من معظم الأطفال.</td>
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<td>26.</td>
<td>طفلي يستطب عمروماً في مرايا سببي.</td>
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<td>27.</td>
<td>أشعر أن طفلي مهتم جداً وينتمي بصورة جيدة.</td>
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<td>28.</td>
<td>يقوم طفلي بعدد قليل من الأشياء التي تزعجني كثيرا.</td>
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<td>29.</td>
<td>طفلي يتعاطى يقفي عندما يحدث شيء.</td>
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<td>30.</td>
<td>طفلي يعضب بصعوبة لأنكه الإسباب.</td>
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<td>31.</td>
<td>نوم طفله أو أكله كان صعباً.</td>
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<tr>
<td>32.</td>
<td>جعل طفلي ينام أفضل ما هو صعب للغاية.</td>
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<td>33.</td>
<td>عند الأشياء التي يقوم بها طفلك التي تزعجني.</td>
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<tr>
<td>34.</td>
<td>هناك بعض الأشياء التي يقوم بها طفلك وتزعج كثيراً حقا.</td>
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<td>35.</td>
<td>تحول طفلك إلى أن يكون مشكلة أكثر مما توقع.</td>
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<td>36.</td>
<td>متطلبات طفلي مه تزيد كثيراً عن معظم الأطفال.</td>
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**الاستاذ الدكتور: إيان دمبسي**

**الاضاءة:**

كلية التربية والتعليم

 جامعة نيوساوث ويلز

 أستراليا

**العنوان:** MBI

**العنوان:** Associate Professor Ian Dempsey

**العنوان:** School of Education

**العنوان:** University of Newcastle

**العنوان:** University Drive

**العنوان:** Callaghan NSW 2308 Australia
Appendix 7.4: Consent Forms for Professional (Arabic Version)

نموذج الموافقة
نموذج موافقة للاخصائيين على المشاركة في هذا البحث:
برنامج تثقيفي لأمهات الأطفال المصابين بالتوحد في الأردن

وافق على المشاركة في هذا البحث وقد قدمت موافقتني بمحض أرادتي.

افهم أن المشروع سوف ينفذ كما هو مبين في بيان المعلومات، والتي ساحتفظ بنسخة عنه.

افهم أنه يمكن أن أنسحب من المشروع في أي وقت دون إعطاء أي سبب لذلك.

اتفق انني سافر إلى المجموعة الرئيسية للاخصائيين وانها سوف تسجل.

اتفق انني سأكون قادرًا على مراجعة وتعديل ومحو المقابلات المنسوبة.

اتفق ان المعلومات ستبقى سرية للباحثة.

كانت لدي الفرصة لطرح الأسئلة والحصول على الإجابة المرضية لي.

اسم الاخصائي (خط واضح من فضلك)  
التلفون:  
البريد الالكتروني:  
التوفيق:  
التاريخ:  
ملخص تقرير نتائج البحث: نعم □ لا □
نموذج الموافقة

نموذج موافقة لمدير المركز على المشاركة في هذا البحث:

برنامج تثقيفي لأمهات الأطفال المصابين بالتوحد في الأردن

وافق على مشاركة مركزي في هذا البحث وقد قدمت موافقتي بمحض ارادتي.

افهم أن المشروع سوف ينفد كما هو مبين في بيان المعلومات، والتي ساحتفظ بنسخة عنه.

افهم أنه يمكن لمركزي الانسحاب من المشروع في أي وقت دون اعطاء أي سبب لذلك.

افهم أنني وافقت على توزيع بيانات المعلومات ونماذج الموافقة على أمهات وأباء الأطفال المصابين بالتوحد وكذلك على الإخصائيين العاملين في مركزي.

انا اتفهم ان مركزي لن يعرف باي من تقارير هذا البحث.

كانت لدي الفرصة لطرح الاستفسار والحصول على الإجابات المرضية لي.

<table>
<thead>
<tr>
<th>اسم مدير المركز:</th>
</tr>
</thead>
<tbody>
<tr>
<td>التلفون:</td>
</tr>
<tr>
<td>البريد الالكتروني:</td>
</tr>
<tr>
<td>التوقيع:</td>
</tr>
<tr>
<td>التاريخ:</td>
</tr>
</tbody>
</table>
Appendix 7.6: Information Statements for Parents (Arabic Version)

الإساتذة الدكتور: أيان ديمبسي
كلية التربية والتعليم
جامعة نيو كاسل
استراليا-

بيان المعلومات لأولياء الأمور من أجل مشروع بحث بعنوان

برنامج تثقيفي لأمهات الأطفال المصابين بالتوحد في الأردن

أعزائي أولياء الأموار

 إنتم مدعوون للمشاركة في مشروع بحث المحدد أعلاه التي سنقوم به السيدة أماني الخلف، كجزء من برنامجها الماجستير تحت إشراف البروفيسور أيان ديمبسي والدكتور كيرى دالي من مركز التربية الخاصة جامعة نيو كاسل استراليا.

لماذا أجري هذا البحث:

 يهدف هذا البحث إلى تفقيع آميات الأطفال المصابين بالتوحد في الأردن وتشمل هذه الدراسة برنامج تثقيفي لهذه الآميات. من أجل تحقيق فعالية البرنامج في زيادة وعي الأمهات، يجري العمل في سمل ان الأمهات وتعظيم مستوى التفقيع لدى هؤلاء الأمهات. سيكون البرنامج مجاناً وليس هناك أي تكلفة للمشاركة فيه.

وستقوم الباحثة أيضاً بالبحث في اراء اباء الأطفال المصابين بالتوحد، وأيضاً اراء الآباء المختصين الذين يعملون مع هؤلاء الأطفال.

من يمكنه المشاركة في هذا البحث:

كلا الوالدين (الام و الآب الذين لديهم اطفال مصابين بالتوحد)

 وقد طلبت الباحثة من إدارة المركز أرسل طلب الموافقة على هذا المشروع وطلب بيان المعلومات في بحثنا هذا.

المشاركون سوف يكونون أولياء أموار الأطفال مصابين بالتوحد في سن الوضع حيث سيكون العدد محدوداً 10 أمهات و10 أباء لأطفال مصابين بالتوحد. في هذه الحالة إذا كان هناك عدد أكثر من 10 مشاركين، سوف يتم اختيارهم على حسب تخصصهم في البرنامج.

سواء اعتمدوا على الوالدين، والذين لن يشاركون في البرنامج سوف يقدموا نبضات ليهم العقل على تعاونهم.

ماذا نستطيع من خيارات في هذا البحث؟

المشاركة في هذه الدراسة هي الخطوة الأولى، فقط الأشخاص الذين أعطوا الموافقة على المشروع هم الذين سيشاركون في المشروع سواء قررت المشاركة أو لا قرارك لن يضرك أو بضر طفلك. إذا قررت المشاركة يمكنك الانسحاب من المشروع في أي وقت دون ألغاء أي ضرب لذلك.

ماذا سيفعل منك أن تفعل?

إذا وافقت لن تزوج على المشاركة في المشروع، سوف يطلب منك ما يلي:

1. سيتم مقابلة الأمهات لمدة تصل إلى 60 دقيقة حول مدى معرفتهم بالعلاج والخبرات المتعلقة بها، سوف تحلل كل أمر

2. سوف تشارك الأمهات في البرنامج التثقيفي لمدة ساعة مرتين في الأسبوع لمدة أربعة أسابيع وسوف يتضمن البرنامج جلسات للبحث، حيث ستقوم الباحثة بأن تلقي وصفة نفسية لديهم خبرة في الاردن، ثم يأتينك مؤخراً دورة تدريبياً لقيادة برنامج أرادي. 

3. ويشتمل إطار البرنامج التثقيفي سلسلة من العروض تقدمها الباحثة لتخفي موضوعات البحث تشمل معلومات عن طيف التوحد وعن صعوبات الاتصال وعن تطوير مهارات التفاعل الاجتماعي مثل تكوين الأصدقاء، تطوير مهارات بتقييم الأمهات.


اللعب والتنزه في الطرقات والتحليق في السلوكيات، والتحدي في القيادة، ومحاولة السيطرة عليها. بالإضافة إلى ذلك، كل جملة سويف تحتاج إلى قرار مهم ومساءلة محددة. وتوقف المنطقية ومشاركة الأفكار والخبرات بين الباحثة والإpgaو بين الأعضاء أنفسهم. وإذا لاي سبب لم يلتزم الأم من حضور جلسة ما ستقوم الباحثة بتزويدها بمعلومات عما تفترض.

4. سيتقدم مقابلة الأمهات بعد الانتهاء من البرنامج التقني لمدة تقرباً 60 دقيقة والهدف من هذه المقابلة معرفة مدى استجابة الأمهات للبرنامج وقياس مدى زيادة في وعي الأمهات لسلوك أطفالهن.

5. سيتقدم مقابلة المجموعة الرئيسية للأبناء لمدة 60 دقيقة لمناقشة كيف يقبل المجتمع الأردني الطفل ذوي الاحتياجات الخاصة والطفل المتوسطي من وجهة نظر الأباء. سوف يقوم الآباء بإكمال مساحيق حول مدى الكفاءة والقدرة الأبوية.

ما هي المخاطر والفوائد المرتقبة على المشاركة؟

هناك القليل من المخاطر المرتبطة على المشاركة في هذه المشروع. خلال المقابلة إذا شعرت بدعم الرجاء سوف تتوقف المقابلة، فورا وانت قد رأى على أي وقت تكون أكثر راحة ولديك الاختيار أيضاً باختصار أوافق المقابلة. إدارة التنمية الاجتماعية من الممكن أن تقدم لك المساعدة من خلال الاتفاق على الرقم 065679327 إذا كنت بحاجة لذلك.

المشاركة في المشروع سوف تزودك بالمعلومات المفيدة حول الطفل المتوسطي الذي من الممكن أن تساعدك، والهدف منها معرفة التجارب التي يمر بها الأهل بالإضافة إلى معرفة مدى فعالية البرنامج التقني على الأمهات.

كيف سيتم حماية خصوصيتك؟

على الرغم من أنه سوف يتم الاستشارة الرقمية لكل المشاركون للسماح للمشاركين بالمشاركة بين نتائج بيانات الأمهات ونتائج بيانات الأباء وهذه الاستشارات الرقمية سوف يتم حفظها في مكان آمن، ولن يسمح للآباء بالإطلاع عليها. هذه البيانات سوف يتم تخزينها لمدة سبع سنوات قبل اطلاقها، ولن يسمح للآباء الإطلاع عليها سوى الباحثة والمشرفين عليها.

بالنسبة للمقابلات سيتم تسجيلها. ونستطيع مراجعتها في أي وقت لأعداها. التسجيلات سيتم ائتماتها مباشرة.

بعد نقل نتائجها إلى الكمبيوتر.

كيف سيتم استخدام المعلومات التي تم الحصول عليها؟

نتوقع هذه الدراسة ستكون عبارة عن رسالة مقدمة من الباحثة أماني الخلف لمنحها درجة الماجستير في كلية التربية في نيوكاسل استراليا. وسيتم استخدام النتائج في المؤتمرات والمجلات. وسيتم توزيع كل المواد المشاركة في البحث سيتم نشرها عن تناول الدراسة. ويمكنك أيضاً اخد نسخة إذا قمت بتزويدها ببريدك الإلكتروني في الخانة المخصصة لذلك في نموذج الموافقة.

ماذا عليك القيام به للمشاركة؟

الرجاء قراء هذا البيان الآن، ثم تقديم جميع الخطوات قبل المقابلة على المشاركة. إذا كان هناك أي شيء لم تفهمه، يرجى استلام الرجاء التواصل مع الباحثة أماني الخلف. أمني في طرق البريد الإلكتروني، khalaf@uon.edu.au أو على الرقم 0777314074، 0103.

إذا كنت ترغب في المشاركة في هذه الدراسة، يرجى ملء نموذج الموافقة المرفق وإعادته إلى الصندوق المخصص. إذا كانت ترغب في المشاركة في هذه الدراسة، يرجى ملء نموذج الموافقة المرفق، وإعادته إلى الصندوق المخصص. إذا كنت ترغب في المشاركة في هذه الدراسة، يرجى ملء نموذج الموافقة المرفق، وإعادته إلى الصندوق المخصص في المركز الذي يحضرك الأبناء. وبعد ذلك سوف تقوم الباحثة أماني الخلف بالاتصال بك هاتفياً لتحديد المكان والزمن المناسبين لك لأجراء المقابلة قبل البرنامج التقني. البرنامج سوف يتم في المركز الذي يشترط فيه أبناء المصاب بالتوحد.

وتفضلوا بقبول فائق الاحترام،

طالب ماجستير طالب الخلف

المشرف على البحث

الباحثة أماني الخلف

الاستاذ الدكتور إينو ديميسي

الدكتورة كيري كاري

السيدة أماني الخلف
Associate Professor Ian Dempsey
School of Education
University of Newcastle
University Drive
Callaghan NSW 2308 Australia

Human-Ethics@newcastle.edu.au
Dr.mohamad safasfeh@hotmail.com
بيان المعلومات لمدير المركز من أجل مشروع بحث بعنوان:
برنامج تثقيفي لأمهات الأطفال المصابين بالتوحد في الأردن

سيدي / سيدي

الأخصائيين وأولياء الأمور في مركزكم مدعوون للمشاركة في مشروع بحث المحدد أعلاه الذي سيقوم به السيد أماني الخلف، كجزء من برنامجها الماجستير تحت إشراف البروفيسور أيان ديمبيسي والدكتورة كيري دالي من مركز التربية الخاصية جامعة نيوكلاس استراليا.

لماذا اجري هذا البحث:

يهدف هذا البحث إلى فيم تجربة أمهات الأطفال المصابين بالتوحد في الأردن وتتضمن هذه الدراسة برنامج تثقيفي لهذه الأمهات. من أجل تحقيق فعالية البرنامج في زيادة وعي الأمهات بمرض التوحد وفهم سلوكي الأطفال التوحديين وتحسين مستوى الثقة لدى هذه الأمهات. سيكون البرنامج مجانًا وليس هناك أي نفقات للمشارك فيه.

وستقوم الباحثة أيضًا بالبحث في أراء أباء الأطفال المصابين بالتوحد وأيضا أراء المتخصصين الذين يعملون مع هؤلاء الأطفال.

من يمكنه المشاركة في هذا البحث:

كل والدين (الأم والاب الذين لديهم أطفال مصابين بالتوحد).

بالإضافة إلى الأخصائيين الذين يقدمون الدعم والمساعدة لأطفال التوحدين.

بالنسبة لأولياء الأمور الذين لديهم أطفال في سن الرضا سيكون عدد المشاركين في المشروع عدداً أقصى 10 أمهات وابناء 10 أباء لأطفال توحد. وفي هذه الحالة إذا كان هناك عدد أكثر من 10 مشاركين يوافقون على المشاركة في البرنامج سيتم اختيار العينة عشوائياً. والذين لن يشاركون في البرنامج سوف يقدم لهم الشكر على التعاون.

اما بالنسبة للأخصائيين العدد سيكون عدداً أقصى 10 أخصائيين يعملون في المركز. في هذه الحالة إذا كان هناك عدد أكثر من 10 مشاركين يوافقون على المشاركة في البرنامج سيتم اختيار العينة عشوائياً. والذين لن يشاركون في البرنامج سوف يقدم لهم الشكر على التعاون.

ماذا لديك من خيارات في هذا البحث؟

البحث يمكن أن يساهم لإجراء هذا البحث على أولياء الأمور والأخصائيين العاملين في مركزكم سيطلب منك توقيع بین المعلومات ونموذج الموافقة على أولياء الأمور الذين لديهم أطفال مصابين بالتوحد وعلى الأخصائيين الذين يعملون مع هؤلاء الأطفال في مركزكم.
والتطور من أولئك الآباء والأمهات الذين وافقوا على المشاركة في القياس بما يلي:

1. سيتم تقييم الأدوات المدمجة إلى 60 دقيقة حسب مدى معرفتهم بالتأثير والخبرات المتعلقة فيها، وسوف تكميل مقياسين حول مدى الكفاءة والقدرة الإبداعية للبحث المتقدم.

2. سوف تشارك الأمهات في البرنامج التدريبي لمدة ساعة مرتين في الأسبوع لمدة أربعة أسابيع وسوف يتم ضمان البرامج المتلائمة لجلسات التوجيه وتسيدمها الابنية المدفوع. سي mieć خلف خصوصية واحدة لديها في الابية لسنة سنتين في مدرسة الابنة وعلاو على ذلك فهي نهبت قريبا دورى تدريبي لقيادة برنامج أرشادي موجه لاباء الأطفال ذوي الاحتياجات الخاصة.

3. ويتم الاطار البرنامج التدريبي سلسلة من العروض تقدمها الباحثة لتغطي موضوع البحث وتستعمل معلومات عن طيف التوحد وعن صعوبات التفاعل الاجتماعي مثل تكوين الأصدقاء، تطور مهارات اللعب والتعرف على النظامية والتحكم في السلوك ومحاولة السيطرة عليها. بالإضافة إلي ذلك كل جلسة سوف تأخير وقت للمشاركة ومشاركة الابنة والابناء بين البنات وابناء وابناء الأعضاء انفسهم. وإذا لا مятия لم تتمكن الأم من حضور جلسة ما ستقوم الباحثة بتزويدها بمواعيد واحدة مختلفات عصر في الجلسة التي لم تلتقي فيها.

4. ستم تقييم الأدوات بعد الانتهاء من البرنامج التدريبي لمدة تقييم 60 دقيقة والهدف من هذا المقابلة معرفة مدى استجابة الأمهات للبرنامج وقياس مدى الزيادة في وضع الأمهات بسلوك أطفالهن.

5. ستم تقييم المجموعة الرئيسية للإباء لمدة 60 دقيقة لمناقشة كيف يقبل المجتمع الاداري الطفل ذوي الاحتياجات الخاصة وسوف يقوم الإباء بتمكن مقاسين حول مدى الكفاءة والقدرة الإبداعية.

إذا هذا كان مناسبًا، تود الأمهات أن يعتمدوا اللقب للتعليم واجراء المقابلات وأجزاء المجموعة وتنفيذ البرنامج التدريبي في مركزكم.

ما هي المخاطر والفوائد المرتبطة بالمشاركة؟

هناك القليل من المخاطر المرتبطة بالمشاركة في هذا المشروع. ولكن المشاركة فيه سوف تزود المشاركين بالمعلومات المفيدة حول التوحد الذي من الممكن أن تساعدهم. وسوف نكون معرفة التجارب التي يمر بها الأهل بالإضافة إلى معرفة مدى فعالية البرنامج التدريبي على الأمهات، وخلال المقابلة إذا شعر أحد المشاركين بمطمئن سوف تتزود المقابلة قروفا وسوف يصح لهم باختيار وقت كافيا ليكون أكثر راحة ولديه اختيار أيضاً باختصار أو اتفاق المقابلة وسيتم تزود من قبل الباحثة بالمعلومات عن الجهات التي يمكن أن تقدم له المساعدة.

كيف سيتم حماية خصوصيتك؟

اسم معلومات المشروع سوف يخزن بها في مكان آمن. كل البيانات سوف يتم تخزينها لمدة سبع سنوات قبل اتقانها، ولن يسمح لأي واحد بالإطلاع عليها. سوف يتم تزويد الباحثين والمشرفين عليها.

بالنسبة للعلامات سيتم تسجيلها. وستنتم مراعاتها يبدها أو إضافة أي معلومة تزودها. التسجيلات سيتم اتخاذها مباشرة بعد نقل بياناتها على الكمبيوتر.

كيف سيتم استخدام المعلومات التي تم الحصول عليها؟

نتائج هذه الدراسة ستكون عبارة عن رسالة مقدمة عن الباحثة آمنة الخلف لمنحها درجة الماجستير في كلية التربوية في نيوكلاند استراليا. وسيتم استخدام النتائج في المؤتمرات والمجلات وسيتم تزويد كل المراكز المشاركة في البحث سيمب بنما عن نتائج الدراسة.

ماذا عليك القيام به للمشاركة؟
المشاركة
للتاكد انك تفهم جميع الخطوات قبل الموافقة على المشاركة. اذا كان هناك اي شي لم تفهمه او
امناء al-khalaf@uon.edu.au
077734074

إذا كنت ترغب في المشاركة في هذه الدراسة، يرجى ملء نموذج الموافقة المرفق وتسليم للباحث.
وتفضلوا بقبول الاحترام.

المشرف على الباحث
طالبة ماجستير
الاستاذ الدكتور ايان ديمبسي

الباحثة كيري دالي
السيدة امانات الخلف

中国企业合资成立该公司的目的有二：首先，为了扩大其在中国市场的影响力；其次，为了满足中国市场的需求。企业通过与中国的本地企业进行合作，可以更好地理解和满足本地消费者的需求，同时也可以降低生产成本。
Appendix 7.8: Information Statements for Professionals (Arabic Version)

بيان المعلومات للأخصائيين من أجل مشروع بحث بعنوان

برنامج تثقيفي لأمهات الأطفال المصابين بالتوحد في الأردن

عزيزي الأخصائي

أنت مدعو للمشاركة في مشروع بحث محدد أعلاه الذي ستقوم به السيدة أماني الخلف ، كجزء من برنامجها الماجستير تحت إشراف البروفيسور إيان ديمبسي والدكتورة كيري دالي من مركز التربية الخاصة جامعة نيوكاسل استراليا.

لماذا اجري هذا البحث:

يهدف هذا البحث إلى فهم تجربة امهات الأطفال المصابين بالتوحد في الأردن وتشمل هذه الدراسة برنامج تثقيفي لهؤلاء الأمهات. من أجل تحقيق فعالية البرنامج في زيادة وعي الأمهات بمرض التوحد وفهم سلوكي ابناءهم التوحديين وتحسين مستوى النفوذ والثقة لدى هؤلاء الأمهات. سيكون البرنامج مجانًا وليس هناك أي تكلفة للمشاركة فيه.

وستقوم الباحثة أيضًا بالبحث في أداء الأطفال المصابين بالتوحد وأيضاً أراء المختصين الذين يعملون مع هؤلاء الأطفال.

من يمكنه المشاركة في هذا البحث:

الأخصائيون الذين يقدمون الدعم والمساعدة للطفل التوحدي.

وقد طلبت الباحثة من إدارة المركز ارسال طلب الموافقة على هذا المشروع وطلب بيان المعلومات في بحثنا هذا.

المشاركين سيكونون 10 أخصائيين. وإذا وافق أكثر من 10 أخصائيين على المشاركة في البرنامج سيتم اختيار العينة عشوائيًا. والذين لن يشاركون في البرنامج سوف يقدم لهم الشكر على تعاونهم.

ماذا لديك من خبرات في هذا البحث?

المشاركة في هذه الدراسة هي بمحس أرادتك. فقط الأشخاص الذين اعطوا الموافقة على المشروع هم الذين سيشاركون فيه. سواء قررت المشاركة أو لا قرارك لن يضرك. إذا قررت المشاركة يمكنك الانسحاب من المشروع في أي وقت دون إعطاء أي سبب لذلك.

ماذا سيطلب منك أن تفعل؟

إذا وافقت على المشاركة في المشروع ستشارك في مجموعة مع غيرك من الأخصائيين لمدة 60 دقيقة والهدف من هذه المجموعة مناقشة كيف يقبل المجتمع الأردني الطفل ذوي الاحتياجات الخاصة والطفل التوحدي من وجهة نظر الأخصائيين.

ما هي المخاطر والفوائد المتوقعة على المشاركة؟

ليس هناك أي مخاطر مباشرة على المشاركة في هذا المشروع. ولكن المشاركة في هذا البحث سوف تزود المشاركين بالمعلومات المفيدة حول الطفل التوحدي التي من الممكن أن تساعدهم، وتتابع هذه الدراسة ستستخدم لمواجهة التجارب التي يمر بها أهل الطفل التوحد بالإضافة إلى معرفة مدى فعالية البرنامج التثقيفي على الأمهات في الأردن.

كيف سيتم حماية خصوصيتك؟
على الرغم من أنه سيتم تسجيل مناقشة المجموعة الرئيسية، إلا أن هذه التسجيلات سيمحتفظ بها مكان أمن، ولم يسمح لأحد بالاطلاع عليها. كل هذه البيانات سيتم تخزينها لمدة سبع سنوات قبل إتلافها، ولن يسمح لأحد بإلتقائها سواء الباحثة والمشرفين عليها.

بالنسبة للمقابلات سيتم تسجيلها. وستستطيع مراجعتها بحذف أو إضافة أي معلومات تريدها. التسجيلات سيتم إتلافها مباشرة بعد نقل البيانات على الكمبيوتر.

كيف سيتم استخدام المعلومات التي تم الحصول عليها؟

نتائج هذه الدراسة ستكون عبارة عن رسالة مقدمة من الباحثة أماني الخلف لنمنها درجة الماجستير في كلية التربية في نيوكلس استراليا. سيتم استخدام النتائج في المؤتمرات والمحاضرات. سيتم تزويده كل المراكز المشارك في البحث سيتم بنفس نسخة من نتائج الدراسة. ويمكنك أيضاً إصدارة مقالة إذا قمت بتزويدنا بريد إلكتروني في الخانة المخصصة لذلك في نموذج الموافقة.

ماذا عليك القيام به للمشارك؟

الرجاء قراءة هذا البيان للتأكد أنك تفهم جميع الخطوات قبل الموافقة على المشاركة. إذا كان هناك أي شيء تفهمه أو لديك أي أسئلة التواصل بعثة أماني الخلف أما على طريقة البريد الإلكتروني - amany.al‐khalaf@uon.edu.au أو على الرقم 0777314047.

إذا كنت ترغب في المشاركة في هذه الدراسة، يرجى ملء نموذج الموافقة المرفق، واعداً إلى الشرف الخصوصي في المركز الذي تعمل فيه. وبعد ذلك سوف تقوم الباحثة أماني الخلف بالاتصال بك هاتفياً لتحديد المكان والزمان المناسبين للإجراء المقابلة حيث ستتم المقابلة في المركز الذي تعمل فيه.

وتفصيلاً بقبول الاحترام.

طالبية ماجستير
المشرف على البحث
الاستاذ الدكتور ايان ديمبي

المشرف على البحث
المشرف على البحث

الدكتورة كيري دالي

السيد أماني الخلف

شكوى حول هذا البحث

تم إعداد هذا المشروع من قبل الجامعة وحقوق وخلاقيات البحث، ورقم الموافقة إذا كان لديك أي مخاوف من المشاركة في هذا البحث، أو لديك شكوك حول الطرق التي يتميز البحث، يمكنك الاتصال بالباحثة هاتفيًا لتحديد المكان والزمان لإجراء المقابلة حيث ستطبق المقابلة في المركز الذي تعمل فيه. 

Human-Ethics@newcastle.edu.au أو التواصل بالدكتور ايان على الرقم 0777314047 أو التواصل بالدكتور محمد مسافه عن طريق البريد الإلكتروني Dr.mohamad safasfeh@hotmail.com.
Appendix 7.9: The Pre-intervention Interviews Questions (Arabic Version)

اسئلة المقابلة قبل البرنامج

1. أخبرني عن نفسك وعن عائلتك؟
2. أخبرني عن طبيعة الحياة في منزلك؟
3. أخبرني عن طفلك التوحد؟
4. كيف عملت للمره الأولى أن هناك شيء مختلف عند طفلك؟
5. ما هي طبيعة العلاقة بينك وبين طفلك التوحد؟
6. أخبرني عن طبيعة سلوكي طفلك التوحد؟
7. ما هي الاستراتيجيات التي تستعملها للتعامل مع طفلك التوحد؟
8. ما هي طبيعة الشيء الصعب الذي يواجهه مع طفلك التوحد؟
9. ما نوع النشاطات العائلية التي تمثلها مع طفلك التوحد؟
10. ما طبيعة النشاط الذي يجعل طفلك التوحد سعيداً؟
11. كيف تكون واقعاً حول إدراة سلوكيات طفلك التوحد؟
12. كيف يتبقي المجتمع الطفل الذي يحظى بحاجات خاصة؟
13. كيف يتغير المجتمع طفلك التوحد؟
14. ما هو نوع الدعم الذي توفره لمساعدة طفلك التوحد؟
15. ما هو مدى رضاك عن هذا الدعم؟

Appendix 7.10: The Post-intervention Interviews Questions (Arabic Version)

اسئلة المقابلة بعد البرنامج

1. كيف تشعر بعد انتهاء البرامج التعليمي؟
2. ما هي الجلسات التي يمكن اضافتها إلى هذا البرنامج؟
3. ما هو مدى الاختلاف في معلومات حول التوحد بعد البرامج التعليمي؟
4. أخبرني عن أي تغير تشعر به؟
5. أخبرني عن أي تغير تشعر به حول سلوكيات طفلك التوحد؟
6. كيف هو طفلك مع هذا الاختلاف؟
7. ما هي ايجابيات وسلبيات البرنامج؟
Appendix 7.11: The Focus Group for Fathers Questions (Arabic Version)

استمارة مجموعة الآباء

1. كيف يتبقي المجتمع لذي الطفل ذوي الاحتياجات الخاصة?
2. كيف يتبقي المجتمع لذك ولتك التوحد؟
3. ما هي أكثر الصعوبات التي تواجهها في المجتمع الأردني كونك والد لطفل توحد؟
4. ما هي طبيعة الدعم الذي تمتلكه لمساعدة طفلك التوحد؟
5. هل انت راض عن هذا الدعم؟

Appendix 7.12: The Focus Group for Professionals Questions (Arabic Version)

استمارة مجموعة الاخصائيين

1. كيف يتبقي المجتمع لذك ذوي الاحتياجات الخاصة؟
2. ما هي أكثر الصعوبات التي تواجهها عائلة الطفل ذوي الاحتياجات الخاصة في المجتمع الأردني?
3. ما هي طبيعة الدعم الذي تمتلكه أسر الطفل التوحد؟