UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFESCIENCES
SCHOOL OF PSYCHOLOGY

# The well- being of mothers of children with intellectual disabilities in Saudi Arabia

By

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## ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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# THE WELL-BEING OF MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SAUDI ARABIA

**By Shatha Khusaifan**

The aims of this thesis were threefold. First, an exploratory study of the Saudi mothers' stress, mental health status, ways of coping, social support provided to them and type of family structure preferred by them, which was achieved by recruiting twenty mothers of children with various Intellectual Disabilities (ID),(Study 1). Second, translating and modifying the original English measures, testing the psychometric properties and finding the new factors of the translated scales by recruiting sample of mothers with Typically Developing (TD) children (N=504) and mothers of ID children (N=513), (Studies 2 & 3). The first set of studies focused mainly on the development of measures that were translated into Arabic. The reliability and validity of all the measures were acceptable. Inserting two additional religious coping items into the Brief COPE did not jeopardise the psychometric properties of the measures, but rather added to its predictive and construct validity. The third aim of this thesis, which was divided into two sub-studies (Chapters 9 and 10) focused on testing the hypothesised model of adjustment to ID by testing all mediating and moderating possibilities. Multiple regression modelling procedures permitted the identification of indirect and direct effects. Results revealed that mothers of children with ID showed higher levels of stress, anxiety and depression than mothers of TD children. In addition, Behavioural Disorders (BD) were significantly stronger than IQ in predicting maternal outcome and only some child and families characteristics have an effect on maternal well-being. Results also provided general support for the proposed model. Religious coping had a moderating effect between BD and maternal stress, between BD and maternal anxiety and between IQ and maternal anxiety. Emotion-focused coping showed a significant moderating effect on BD and maternal anxiety. Regarding social support, satisfaction with support (SPS) showed a nearly significant moderating effect between BD and maternal anxiety. The helpfulness of social support (FSS) showed a nearly significant moderating effect between IQ and maternal stress. Whereas, network size (FSS2) had a significant moderating effect between IQ and maternal stress.

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“I CANNOT DO EVERYTHING; BUT STILL I CAN DO SOMETHING; AND BECAUSE I CANNOT DO EVERYTHING; I WILL NOT REFUSE TO DO THE SOMETHING I CAN DO.”

Helen Keller (1880-1968)

“ANYTIME YOU SEE SOMEONE MORE SUCCESSFUL THAN YOU ARE, THEY ARE DOING SOMETHING YOU AREN’T”

Malcolm X (1952-1965)

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# CHAPTER 1

# INTRODUCTION AND OUTLINE OF THESIS

Stress is a part of life and some level of stress is positive and necessary to stimulate an individual to achieve and be successful. However, a high level of stress can cause physiological and psychological problems because of its negative effects on physical or mental health (Brodfield & Fones, 1985; Kaiser & Polezynski, 1982).

Research has supported the notion that parents of children with disabilities, especially with Intellectual Disability (ID), are at risk of a higher level of stress, anxiety and depression than parents of Typically Developing (TD) children. Nevertheless, studies which have focused on the effect of ID on families described how some parents of intellectually disabled children showed lower levels of stress, anxiety and depression. Those studies presented models that described the importance of coping strategies and social support which might be called the 'adaptation process'.

In the literature different models of stress and coping have been tested with different kinds of disabilities in different societies. However, little is known about the effect of intellectual disabilities on maternal mental health in Arabic Middle-Eastern countries.

This thesis focused on the application of Vallerand's cross-cultural translation model (Vallerand, 1997) to Saudi mothers of TD children and those with ID children by interviewing mothers (Study 1) and described the development of Arabic measures; Hospital Anxiety and Depression Scale (HADS), Parenting Stress Index-Short Form (PSI-SF), Social Provision Scale (SPS), Family Support Scale (FSS), and Brief COPE; and the testing of their psychometric properties (Study 2). In addition, it focused on the relationship between ID and maternal well-being (stress, anxiety and depression) in mothers of children with ID by testing a model of moderating and mediating paths (Study 3).

The thesis was organised in 11 chapters as follows: Chapter 2 provided a conceptual framework of the stress and coping models of adjustment to disabilities, Chapters 3 and 4 focused on the theoretical frameworks that have been used to explain stress and mental health in parents and especially mothers of disabled children in both western and non-western cultures. Most studies in these chapters involved mothers of ID children. Chapter 5 explained in detail the background of Saudi Arabia, its history, geography, family system, disability and health services, education system etc. Chapter 6 explained the methodological issues of the whole thesis.

Chapter 7 described interviews with Saudi mothers of ID children in order to test their point of view about themselves, their children, the most useful coping strategies used by them, the kind of social support they received and their mental health status as they assessed it. Results from this study provided a guideline for the following chapters for modification of the translated instruments, to include or exclude items reflecting their experiences.

Chapter 8 considers the second study, which focused on the development of the Arabic versions of questionnaires (PSI-SF, Brief Cope, SPS, FSS, and HADS) using Vallerand's cross-cultural translation process (Vallerand, 1997). The modified and translated measures were administered to a large sample of mothers of TD and ID children. These data were used to test the psychometric properties of these measures of Arabic translated versions and the effect of the additional items on the psychometric properties of the original scales (Chapter 9). Levels of parenting stress, anxiety, depression, social support and coping were also assessed in a general population sample to allow comparisons (Chapter 9).

In Chapter 10 differences of IQ and Behavioural Disorders (BD) were tested as predictors of maternal well-being. In addition, the hypothesised model was examined using multiple regression models in a sample of mothers of children with ID after controlling for child, mother, and family characteristics. Both mediating and moderating effects of coping, stress, social support and family structure were investigated in Chapter 10.

In Chapter 11 findings and their relevance for developing a better understanding of the process of adjustment to disability were presented. Finally, methodological limitations and directions for future research were also discussed in Chapter 11.

# CHAPTER 2

# CONCEPTUAL FRAMEWORK

## 2.1. Introduction:

It is well known that parenting is a hard task, demanding from the individual both dynamism and maturity. Parents cannot take vacations from being a member of a family, it is definitely a "full time occupation" (Amaral, 2003. p.15).

If these parents receive a diagnosis of disability for their new-born baby, the loss of the fantasised child and the discrepancy between the expectation and reality precipitate a crisis reaction (Styles, 1986). As a result, parents of children with disabilities usually report more stress than parents with children without disabilities (e.g. Baker et al., 2002; Beckman, 1991; Dyson, 1991; Hadadian, 1994; Kazak, 1987; Margalit & Ankonina, 1991; White & Hastings, 2004).

Since parenthood in itself represents a notable challenge, how much more stress is added when the child has disabilities? Do the child's disabilities alone affect the parent's stress, or is the parents' distress the result of a combination of other factors? Some of these questions remain unanswered or unclear (Amaral, 2003).

A challenge encountered by healthcare professionals when working with disabled children and their families is the need for sensitive awareness of the special stressors placed on the family unit. To provide professional help to these families, it is necessary to obtain a better understanding of the process that influences stress and its outcome.

This chapter is divided into two main sections. The first one briefly discusses the theoretical antecedents of coping concepts. The second section describes different models of stress and coping. All models are outlined here in reference to the family with a disabled child. Illustration of the concepts from the models will be delineated with regard to the proposition of the study and the area of research interest.

Some of the major models that address concepts central to family adaptation to chronic illness and caregiving are: the ABCX model (Hill, 1949); the double ABCX model (McCubbin & Paterson, 1983); the family adjustment and adaptation response (FAAR) model (Patterson, 1988); the process model of stress and coping (Lazarus and Folkman, 1984); Pearlins model (Pearlin, et al., 1981); the disability-stress-coping model self appraised model (Wallander et al., 1989); and the transactional stress and coping model of adjustment to disability (Thompson et al., 1993).

## 2.2.Theoretical antecedents of the coping concept:

Before moving on to describe the main models of stress and coping in the next section, it is important to briefly mention that the concept of coping is found in two different branches of the theoretical literature. One is derived from the tradition of animal experimentation, and the other from psychoanalytic ego psychology.

### 2.2.1. Evolutionary theory and behavioural adaptation:

This theory examined the process of adaptation to the environment according to which survival is contingent on the animal discovering what is predictable and controllable in the environment in order to avoid, escape, or overcome harmful agents (Folkman, 1991). In the animal model, according to Folkman (1991), coping is frequently defined as an act that controls aversive environmental conditions, thereby lowering psychological disturbance.

The two central elements in Darwinian theory are variation in reproduction and inheritance by living organisms and natural selection for the survival of the fittest. Evolutionary thought and human ecology have focused primarily on communal adaptation. Human beings cannot adapt to their environment alone, they are interdependent and must make collective efforts to survive.

Communal adaptation is an outgrowth of individual adaptation and of specific coping strategies that serve to contribute to group survival and promote human community (Moos& Schaefer, 1993).

### 2.2.2. Psychoanalytic ego psychology:

In this theory, coping is defined as realistic and flexible thoughts and acts that solve problems and thereby reduce stress. The main difference between the treatment of coping in this model compared to Darwin's animal model is the focus on ways of perceiving and thinking about the person's relationship with the environment (Amaral, 2002).

Freud attributed behaviour to the drive to reduce tension by satisfying sexual and aggressive instincts. In essence, ego processes reduce tension by enabling the individual to express sexual and aggressive impulses indirectly without recognising their true intent. The main functions of ego processes are defensive (to distort reality) and emotion-focused (to reduce tension) (Moos & Schaefer, 1993). According to this theory, behaviour is not ignored. Rather, it is considered less important than cognition (Amaral, 2002).

## 2.2.Models of stress and adjustment to disability:

Before moving on to describe the models, it is important to define adaptation and adjustment because both of these terms have been used in the stress and coping literature. Some of the previous studies used them interchangably, seeing no difference between them. However, adaptation is defined as the extent to which an individual can accommodate the demands of the stressful situation (e.g. find resources, change life style), whereas adjustment is defined as psychological balance or freedom from abnormality in the face of pathological circumstances (Pless & Pinkerton, 1975).

### 2.2.1. ABCX model:

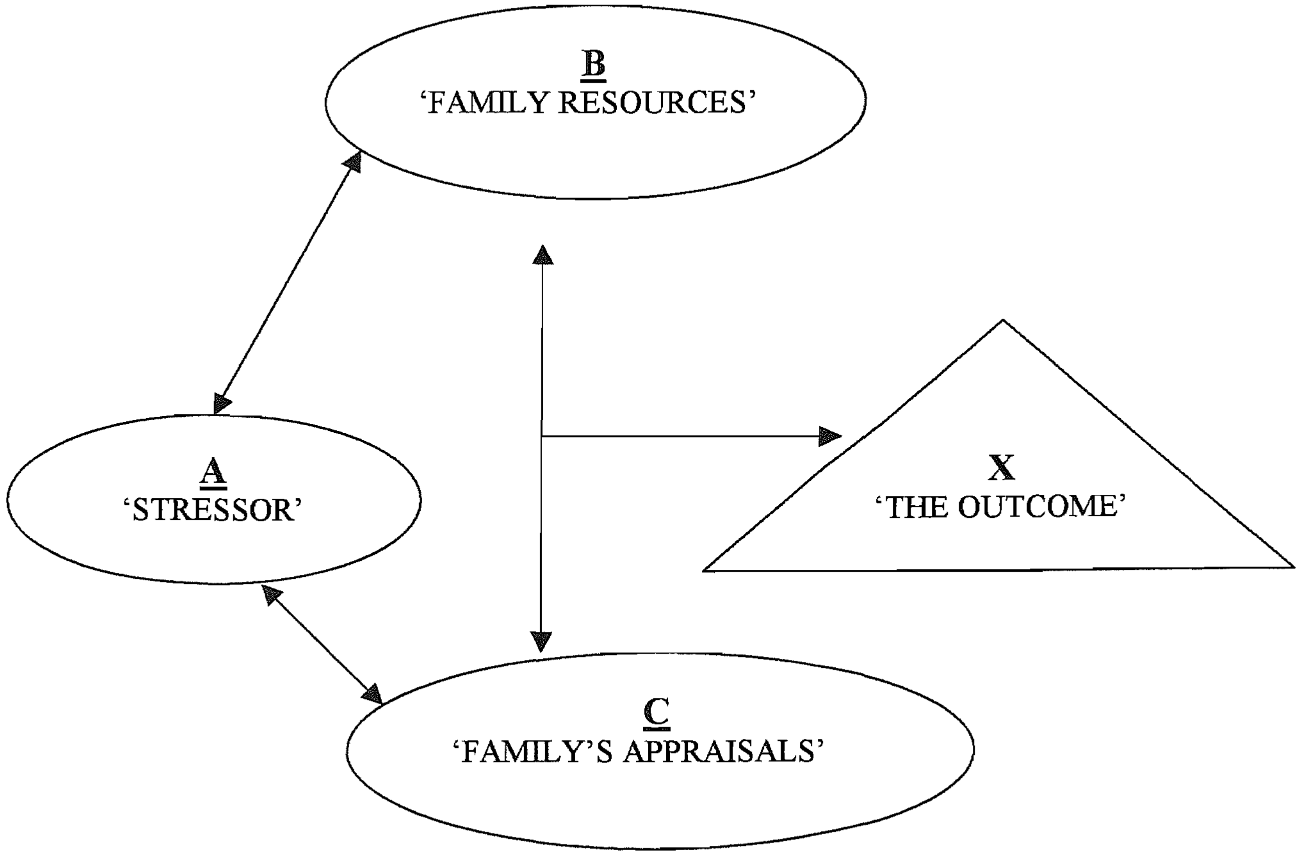
The ABCX model emerged from the field of sociology and the conceptualisation of the process of family reaction to stress events. One of the earliest multidimensional models is the work of Hill, (1949/1958) and illustrates the application of stress and coping theory to family functioning. Hill had studied families where the stressful event was the separation of soldiers from their wives and children during the Second World War. This model of family functioning was probably the first model to combine the family factors of stress, resources, and appraisals of the stressor in an attempt to understand the status of family functioning (Ezinwany, 1999). The "ABCX model" emphasised that the difficult demands on a family can be mediated by internal and external resources (Heller & Factor, 1993). Hill (1949) proposed a model of stress that is often used in the general family literature as well as in relation to families of children with disabilities or chronic illness (Keller, 1999). Moreover, this model could be used to predict aspects of successful family adaptation to homecare of children with intellectual disabilities (Bristol, 1987). It has provided the foundation for much of the family crisis research in the past four decades (e.g. Calgary, 2002; McCubbin & Patterson, 1983; Wikler, 1981).

This model suggests an interaction of three factors: (A) a stressor event which was defined by McCubbin and Paterson (1983) as "a life event or occurrence in or impacting upon the family unit which produces change in the family system" (p.88), (B) a family's resources for dealing with stress (i.e. resources of coping), (C) the family's appraisal of the stressor. These three factors produce (X), which is either the family crisis, or the successful family adaptation (Orr, Cameron & Day, 1991). (Figure 1).

As shown in figure (1), there is no direct relationship between a family stressor (A) and the occurrence of family crisis (X). It hypothesises that the two important variables are the resources available to the family (B), and the family's perception or appraisal of the stressor event (C) and that these mediate the effects of stressors on family functioning (Ezinwany, 1999).

Further expanding the ABCX model, Cole (1986) provided a theoretical framework for understanding the roles of family stressors and resources in influencing the decision to place a child with developmental disabilities out of the home. When stressors related to the child combine with other family stressors to produce a crisis, the family may cope by removing the stressors, including placing the child out of the home (Heller & Factor, 1993).

Figure 1: The ABCX model



### 2.2.2. Double ABCX model:

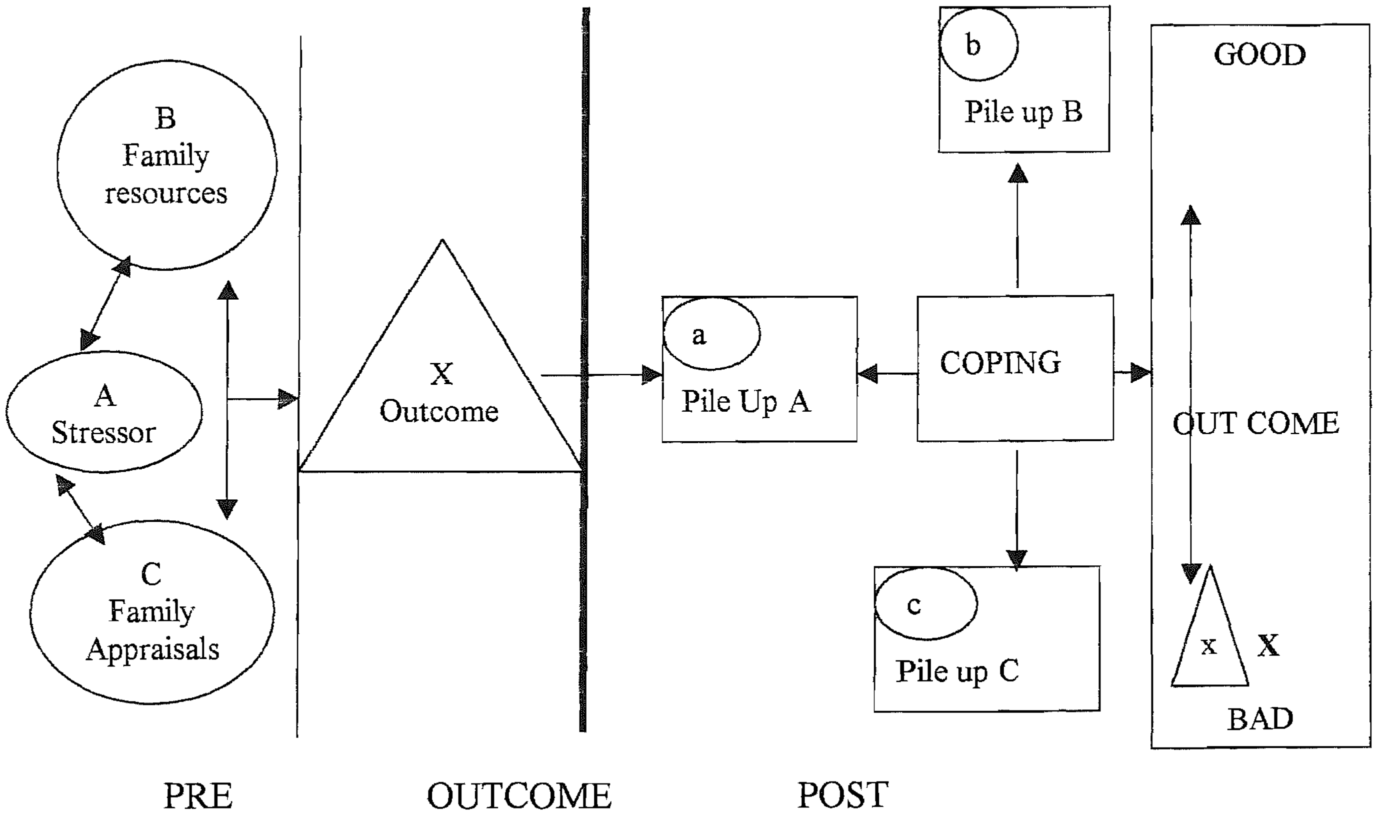
McCubbin and Paterson (1983) developed a variation of Hill's ABCX model by expanding it to the double ABCX model to account for the family's perception of the multiplicity of stressors and factors that can emerge during a family crisis. They extended the original model by adding two feedback loops (Figure 2): A positive feedback loop which they called "bonadaptive" (e.g. Positive child behaviours, continued promotion and maintenance of positive family system), and a negative adaptation which is "Maladaptive" (e.g. worsening of the child's behaviours leading to overall deterioration of the family system).

The model has served as the foundation for many studies that have examined the stress of disabilities in the presence of normative and non-normative events. Stressors rarely occur as one-time events or situations that lead to crisis. The model reflects real life where families usually experience many stressors simultaneously and in repeated patterns. This is recognised in the pre-crisis part of the model.

In this model, (aA) is described as an event or life transition that can produce change in the family system in boundary definition on roles or relationships. It addresses the pile-up of family stressors and strains. The (bB) factor is described as the family's ability to cope with the event. It  (bB) deals with the existing resources of the family, which can be tangible, such as money, or intangible, such as self-esteem, personal resources include innate intelligence, knowledge and skills, personality traits (e.g, the desire for control), physical and emotional health, a sense of mastery and self-esteem. The (cC) factor is described as the meaning that the family attributes to the crisis situation or the event. This "meaning" always factors the family's values and attitudes associated with stress and crisis. The aA, bB, and cC factors combine to influence the family's ability to prevent the stressor from evolving into a crisis (Keller, 1999). The "xX" factor is defined as family adaptation, the outcome of family efforts to bring a new level of balance and fit to family level of functioning. Adaptation reflects a continuum of outcomes with bonadaptation at one end and maladaptation at the other. When coping strategies do not result in restoration of family stability, maladaptation occurs.

Applying the double ABCX model to the family of a child with ID and severe physical disability, the family may need assistance in caregiving in order to maintain the child in the home (aA), the family's ability to adjust their schedules, negotiate roles and tasks and demonstrate the flexibility needed to have other caregivers in the home, may depend on the quality of relationship and level of cohesion that exist in the family (bB); how the family defines the event; the child's disability, their need to learn new skills, the need for support services, will give meaning to this life event for them (cC). Individual families will respond differently to ABC resulting in positive adaptation and change or a family crisis (X) (Keller, 1999).

Figure 2: The double ABCX model (McCubbin & Paterson, 1983)



### 2.2.3. The Family Adjustment and Adaptation Response (FAAR) model:

The Family Adjustment and Adaptation Response (FAAR) model is an interactive model that describes the process by which families achieve adjustment and adaptation (Patterson,1988). The model places adjustment and adaptation on a continuum from good to poor. Good outcomes are demonstrated by the physical and mental health of individual family members, optimal role functioning in the system, and maintenance of a family unit which can accomplish its life cycle task (Keller, 1999).

As the family attempts to maintain balanced functioning, the outcomes of these attempts are conceptualised as two phases, family adjustment and family adaptation (Figure 3). These two phases of adjustment and adaptation are separated by an additional family crisis, which can be a particular event in time or a source of continuous stress, such as disability in a family member (Patterson & Garwick, 1994).

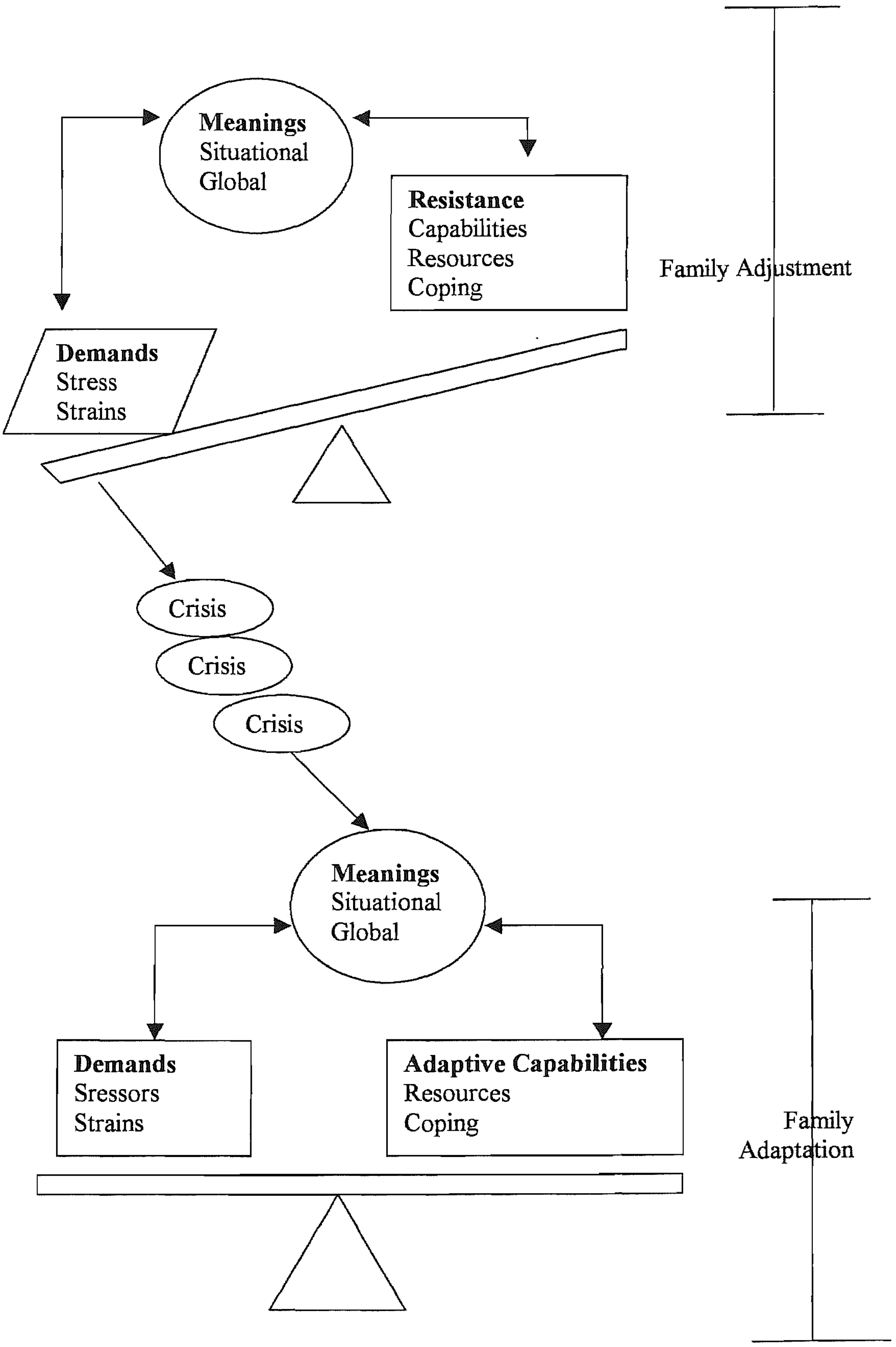
1. The adjustment phase: assesses a stable period during which the family rejects change and attempts to meet demands with existing capabilities. Or it might denote the minor changes which families have made in their family function to meet the daily demands of raising their child (Beck, 2002; Keller, 1999).

2. The adaptation phase: is the second order change which occurs as a result of the family's attempt to restore homeostasis by acquiring new additional coping, changes in their behaviours, reducing demands, or changing their view of the meaning of the situation.

During both phases (the adaptation and the adjustment) family members appraise their situations in terms of demands and capabilities. The model asserts that families use their resources and coping behaviours (i.e. capabilities) to confront or meet the stressors and strains (i.e. demands) they encounter when faced with major stress such as disability in a family member (Keller, 1999). However, the meanings the family attribute to demands placed on them, as well as their interpretation of their ability to deal with what is happening are crucial to the family's adaptation (Rolland, 1994).

Over time, the family members will experience repeated cycles of adjustment and adaptation in response to both normal life-cycle of adjustment and adaptation in response to normal life-style transition and/or major life stressors such as taking care of a disabled child.

Figure 3: Family Adjustment and Adaptation response model (FAAR, Paterson, 1988)



### 2.2.4. The Process model of stress and coping (Lazarus & Folkman, 1984):

In 1966, Lazarus first formulated a theory of psychological stress based upon the construct of appraisal of perceived threat. He postulated that appraisal, which is dependent upon individual differences in cognition and motivation, accounted for much of the stress response (Altmaier, 1995). Later, Lazarus and Folkman (1984) conceptualised coping as the base upon which appraisal of perceived stress and the perceived effectiveness and availability of personal resources to deal with the problem is built.

In this model, successful coping results from a match between appraisal and coping (Folkman et al., 1986). The model suggests that distress is the result of the interaction between the stressful event, personal resources, cognitive appraisal of the stressful event, and coping resources (see Figure 4).

The Lazarus and Folkman (1984) model emphasises a coping process in which the outcome of the stressful event is mediated by the nature of individual appraisals (primary and secondary) in transaction with coping.

1. Primary appraisal: is a cognitive event in which a potentially stressful situation is evaluated in terms of its significance for the well-being of the individual or loved one (Folkman et al., 1986)

   Three types of primary appraisals can be distinguished:

   a. Irrelevant: when a person has no divestment in the outcome and has nothing to lose or gain in transaction.
   b. Benign-positive: when a situation is constructed as positive or as enhancing the well-being of the individual.
   c. Stressful appraisal which can take three form: harm/loss, threat and challenge (Lazarus & Folkman, 1984).

2. Secondary appraisal: this involves the evaluation of coping resources and options in determining what might and can be done in response to that event (Lazarus & Folkman, 1984). Coping is the process of executing that response (Carver, Scheier & Weintraub, 1989).

Lazarus and Folkman (1984) also argued that the stress of an individual experience is not a simple function of the number of demands placed on that individual. If personal resources are adequate to meet those demands, the individuals can successfully adapt, even if the environmental demands are considerable. Folkman et al.(1986) proposed that in case of stressful situations that are chronic with little opportunity for personal control, individual factors such as personality variables play the greatest role.

This model (Lazarus & Folkman, 1984) argues that the process of coping mediates the effects of stress on an individual's well-being. The two key aspects of the coping process are *coping resources* and *coping strategies.*

**a. Coping resources:**

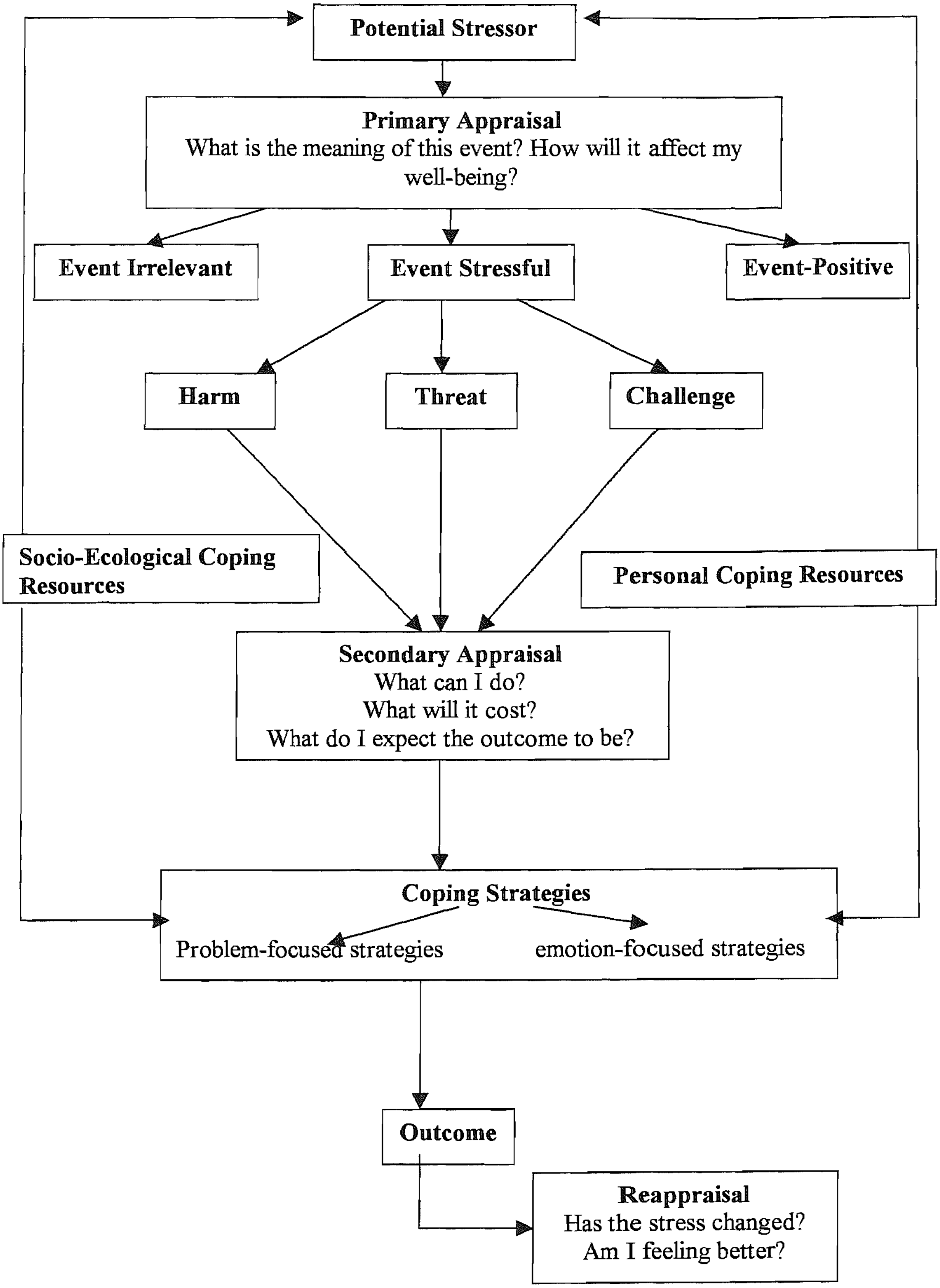
Lazarus and Folkman conceptualised individuals as having five categories of *coping resources*: social networks, problem-solving skills, general and specific beliefs, utilitarian resources, and health/energy/morale (Frey, Greenberg & Fewell, 1989).

**b. Coping strategies:**

The action and thoughts a person uses to deal with stress are known as coping strategies (Beresford, 1996). There are two broadband *coping strategies* that are employed in the face of disturbing events: problem-focused coping and emotion-focused coping. Beresford (1996) pointed out that coping strategies either act on the source of stress (problem-focused coping) or seek to alleviate distressing emotions caused by a stress (emotion-focused coping). *Problem-focused* coping includes cognitive and behavioural problem-solving efforts to alter or manage the source of stress, whereas, *emotion-focused* coping strategies attempt to reduce or manage emotional distress (Folkman & Lazarus, 1980; Essex, Seltzer & Krauss, 1999). Lazarus and Folkman (1984) posited that when the source of stress is out of the control of the individual, problem-focused coping efforts do not produce the desired results, and emotion-focused coping might be the preferred response.

This model has guided the research of stress, coping and adjustment in the area of adjustment to disability and chronic illness. However, Hofall (1989) (cited in Aldwin, 2000) criticised the emphasis the model put on the role of the individual appraisal, considered to be a ‘subjective’ factor. He believed that personal cognitive process and more objective factors might be important in stress and the adjustment process as well.

Figure 4.: The Process model of stress and coping (Lazarus & Folkman, 1984) (from Beresford, 1994)



### 2.2.5. Pearlin's model:

In this model Pearlin et al. (1981) identified the occurrence of discrete events and the presence of relatively continuous problems as being disruptive to an individual's equilibrium. Disequilibria then evoke changes leading to vulnerability to stress (Kuster, 2002).

Three major conceptual domains are thought to describe the stress process: sources of stress, mediators of stress, and manifestation of stress (Pearlin et al., 1981) (Figure 5).

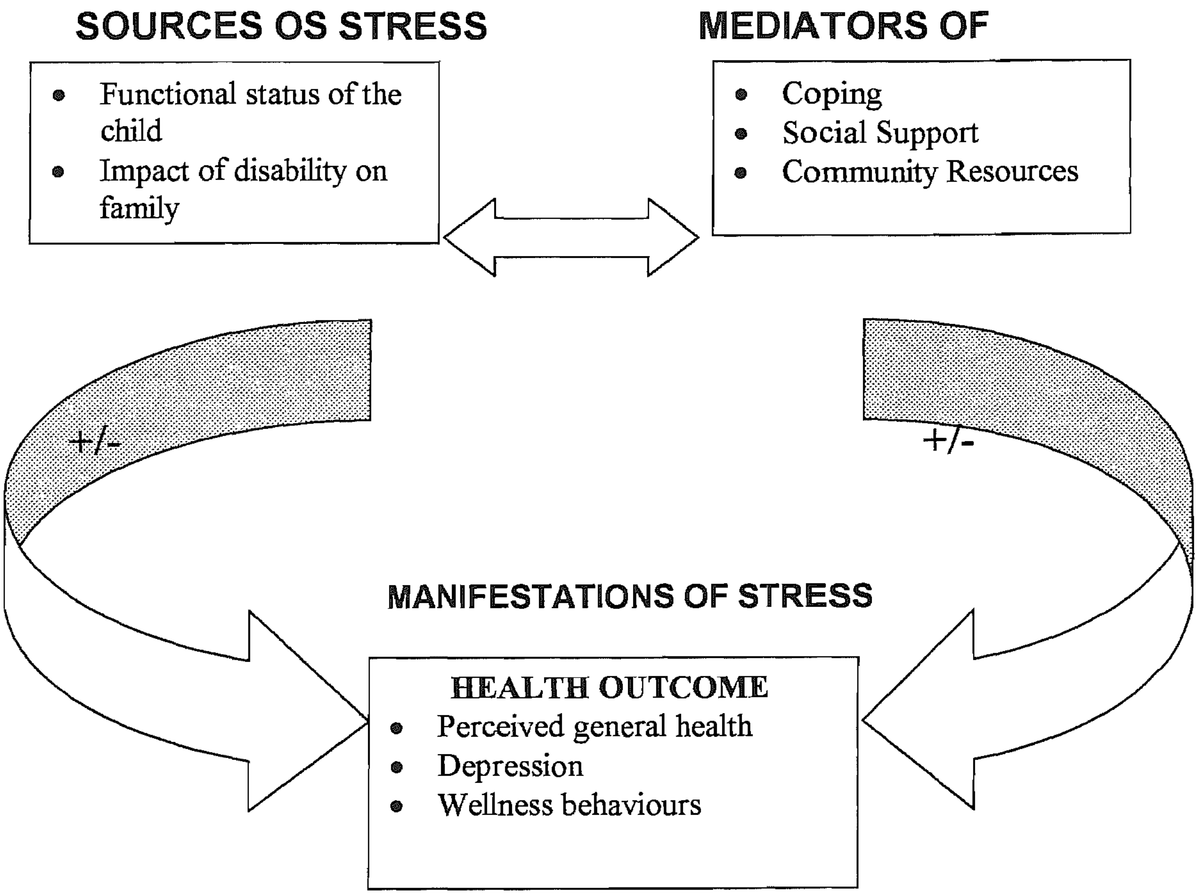
1. Sources of stress: include eventful experiences, life strain, and self-concept. In addition, it includes the daily impact of a stressful situation identified as 'chronic life strain'. Discrete life events and relatively continuous problems are considered to be sources of stress (Pearlin et al., 1981)

2. Mediators of stress: are the variety of behaviours, perceptions, cognitions, and resources that a person uses or possesses to alter or mediate the meaning of events that confront them (Pearlin et al., 1981). There are a number of personal, family and community resources vital to the successful adaptation of the family to stress such as formal and informal social support (Kuster, 2002).

3. Manifestation of stress: is the response of the organism to the conditions that, either consciously or unconsciously, are experienced as noxious (Pearlin et al., 1981). These responses of the individual may be revealed as emotional, physical, or behavioural health outcomes. Health outcomes are manifestations of stress that affect the perceived general health, depression, and performance in wellness behaviours (Kuster, 2002).

In 1990 a fourth domain was added to the stress process and caregiving model by Pearlin et al. (1990). This domain is the 'context of stress' or the 'Background characteristics' such as gender, age, ethnicity, socio-economic class, education and occupation. These are in addition to the situation factors such as the care recipient's age, illness progress, symptoms, and treatment needs.

Figure 5: Pearlin's et al., model (1981) (From Kuster, 2002)



### 2.2.6.The disability-stress-coping model:

The risk and resistance model of adaptation of mothers of chronically ill and disabled children was proposed by Wallander et al. (1989) and Wallander and Varni (1992). The model is built upon the conception of Pless and Pinkerton (1975), Moos and Shcaefer (1984) and Lazarus and Folkman's (1984) transactional stress and coping model.

This model defines parental adjustment to their child's disability in terms of the balance between risk and resistance factors. The model hypothesises that risk factors (such as disease or disability or psychological problems) and resistance factors (such as social-ecological factors, interpersonal factors, and stress processing) can be identified empirically and may provide heuristic guidance for the development of interventions (Figure 6).

The model recognises that parents' adaptation cannot be explained entirely by the presence of the disabled child. This model focuses on explaining the different outcomes and complex bi-directional interrelationship *of risk factors* such as disability and resistance factors such as social-ecological factors, interpersonal factors, and stress processes (Figure 6).

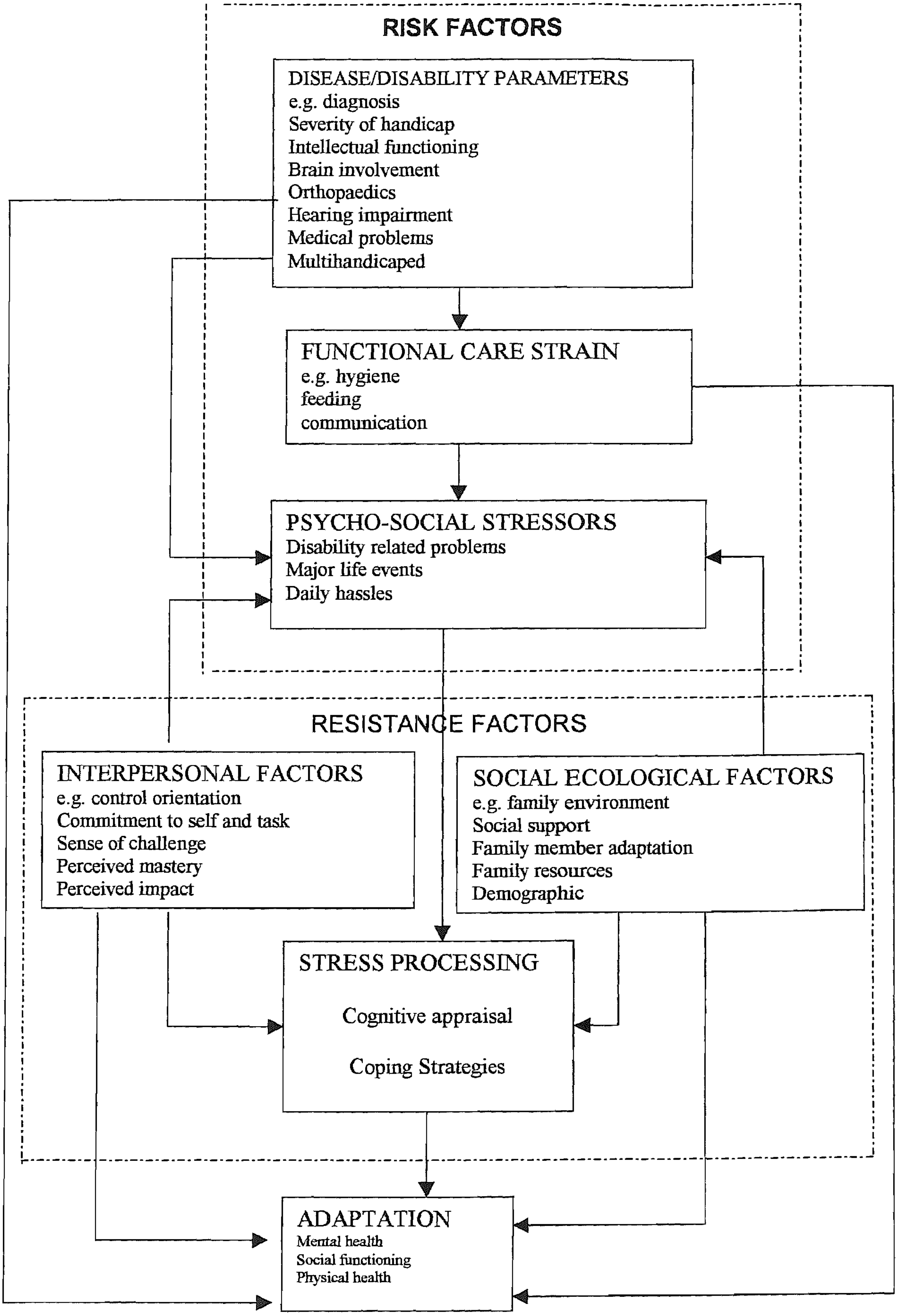
On the other hand, resistance factors in this model have received varying levels of attention. These factors are:

1. Stress processing conceptualised as appraisal of the situation and implementation of coping strategies to manage the situation (Wallander, Varni, 1998). For example, emotion-focused coping is associated with maladjustment of the mother of disabled children (Thompson et al., 1992).
2. Socio-ecological factors have been found to be associated with family support and social support (Krongberger & Thompson, 1992; Thompson et al., 1994).
3. Interpersonal variables have received attention in the coping literature. For example, Buttler and Meichanbaum (1981) suggested that appraisal of the person's problem-solving ability may be an important variable in the problem-solving process. Hepner and Krauskopfs (1987) suggested that coping and personal problem-solving can be viewed as synonymous

processes that serve a vital function in the way a person processes information about him/herself, the environment, and the problematic situations.

Both risk and resistance factors have direct and indirect effects on adjustment. For example, the disability in one member of the family affects parents' adjustment. However, there is also an indirect effect via increased levels of functional care strain, and psychological stress. Wallander and Varni (1992) concluded that not only the medical or the physical status, but also psychological processes are helpful in explaining adjustment.

Figure 6: The disability- stress-coping model (Wallander et al., 1989) (in Noojin, 1997)

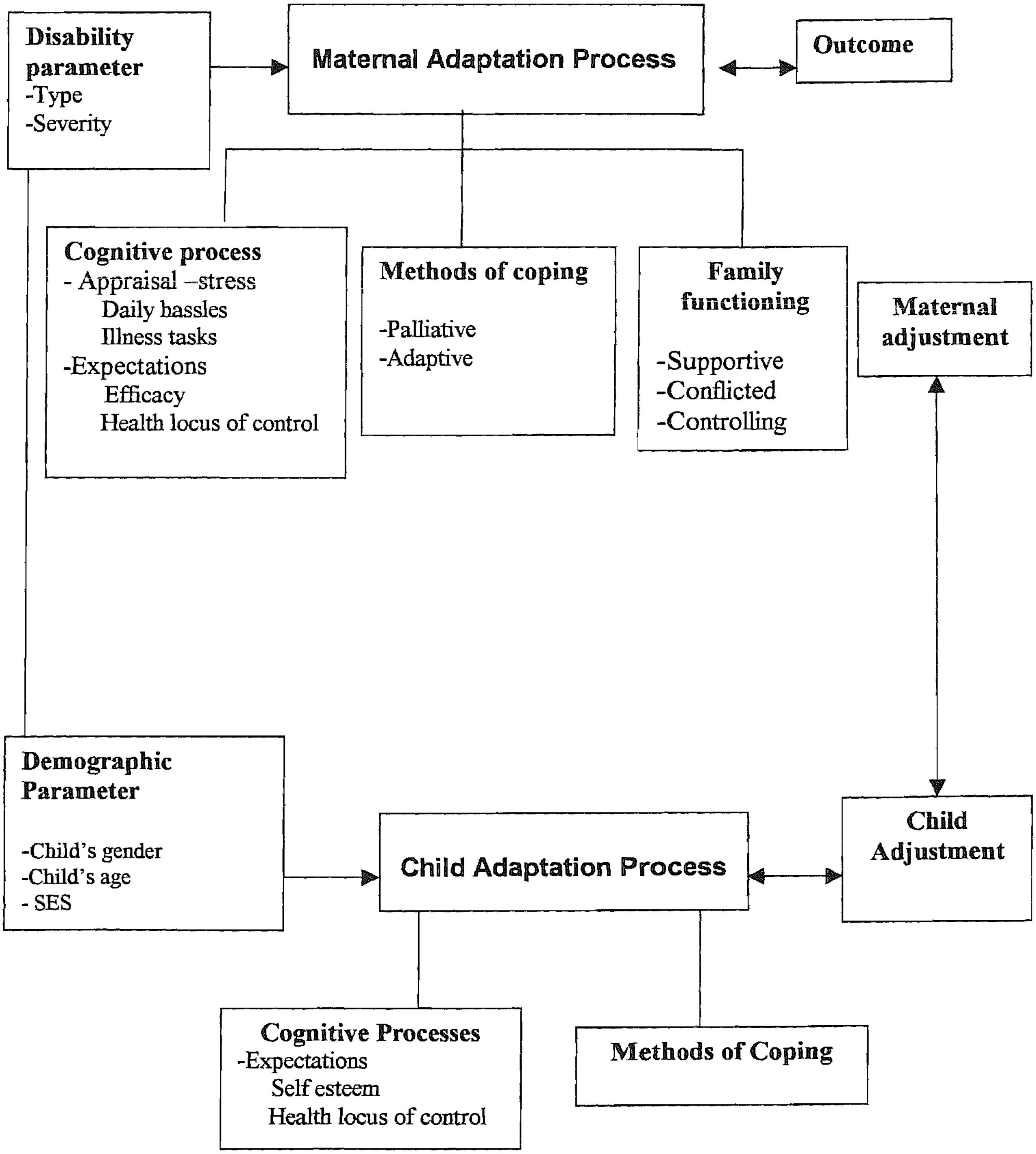


### 2.2.7. The transactional stress and coping model of adjustment to disability:

This model views disability as a potential stressor (Thompson et al., 1993, 1994; Thompson, Gil, Burbach & Keith, 1993). However, the model differs from the disability-stress and coping model by emphasising that the levels of stress and adjustment experienced by other family members mediate the psychological adjustment of an individual. In addition, this model emphasises the importance of interaction between family and child adjustment.

In Figure 7, disability is perceived as a stressor, to which both parents and child need to adjust. It shows that adaptation processes that mediate the relationship between disability parameters and adjustment, which is defined here as a function of the adjustment of individual family members and their interrelationship. This process of adaptation includes the cognitive process of appraisal of stress, expectation of locus of control and efficacy of coping and family functioning. Finally, the model incorporates the notion of parents' adaptation as parent and child adjustment equally affect each other.

Figure 7: The transactional stress and coping model of adjustment to disability (Thompson et al., 1994)



### 2.2.8.Self appraised problem-solving ability and stress, coping, and adjustment model:

This model delineates the influence of the parental belief system on the multiple constructs in the risk and resistance model (Wallander et al., 1989) as a response to the increasing emphasis of individual factors in stress reactions. There are three major components of self-appraised problem-solving which are: problem-solving confidence, approach-avoidance style, and personal control. It is important to consider these three components when we investigate adjustment (Wilson,2002).

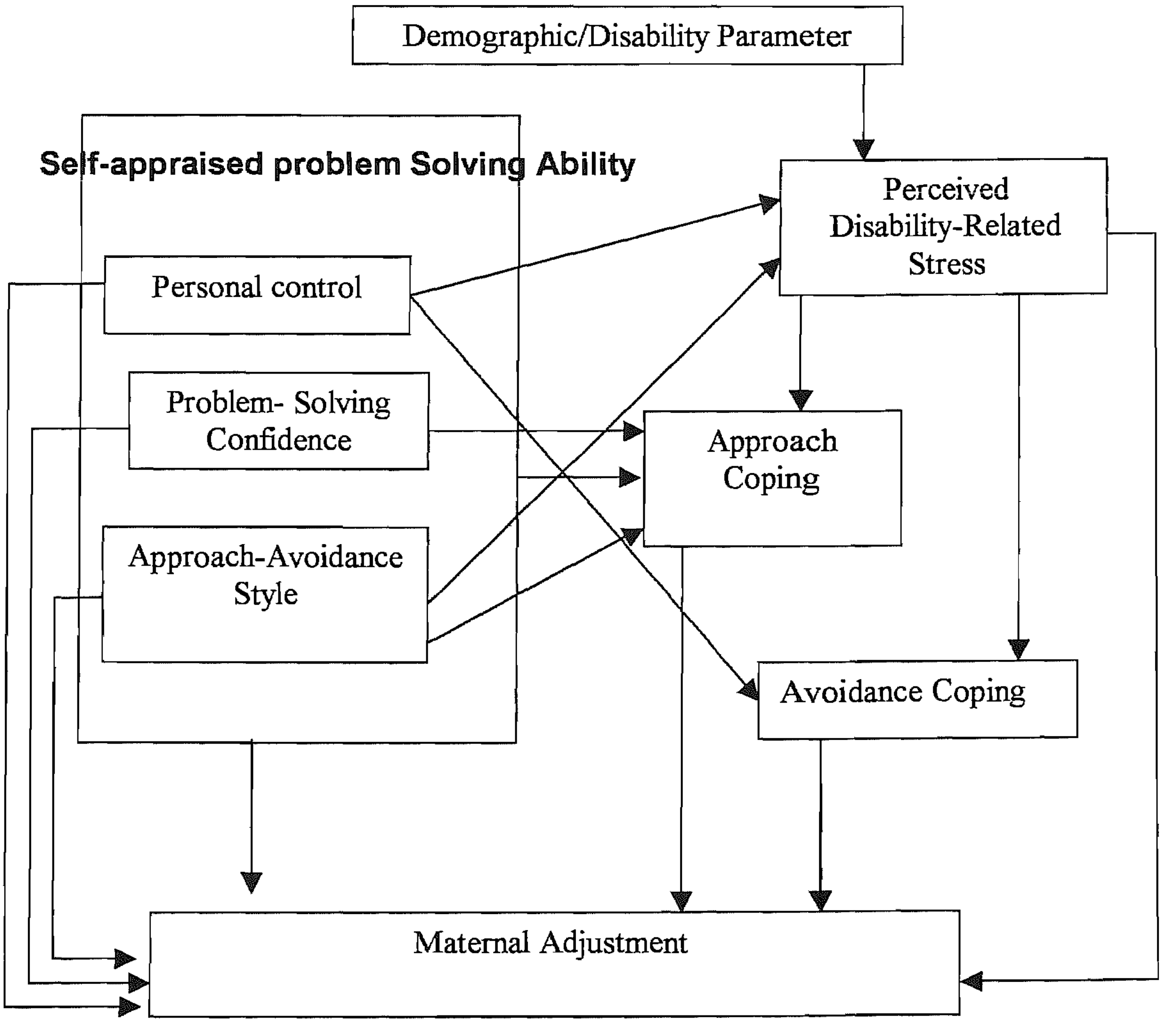
Heppner and Paterson (1982) Problem Solving Inventory (PSI) identifies three primary components of self-appraised problem-solving:

1. The problem-solving confidence factors are the degree of confidence in problem-solving abilities
2. The approach-avoidance factors are a cognitive-behavioural skill in defining problems and formulating solutions
3. The personal control factors are the perceived ability in regulating emotional experience in problem-solving situation.

Each of these components is substantially directly and indirectly related to maternal coping and adjustment in caring for children with disability (Noojin, 1997). This model shows that in the families of disabled children, the mother's self-appraised problem-solving ability strongly influences overall psychological adjustment.

Mothers who perceive that they are effective problem-solvers generally report fewer emotional and physical problems (Noojin, 1997). Mothers who report better psychological adjustment also have a higher level of confidence in their problem-solving ability, tend to use approach-coping strategies rather than avoidance-coping strategies, and feel in control of their behaviour and emotions while problem solving. In addition, mothers who report the highest stress also report a tendency to avoid problems and feel out of control of their behaviour and emotions while problem solving (Noojin, 1997). Moreover, the severity of the child's disability has a much smaller total effect on maternal adjustment than perceived problem-solving abilities or perceived stress psychological process (Noojin, 1997).

Figure 8: Self-appraised problem-solving ability and stress, coping, and adjustment model (Noojin, 1997)



## 2.3. Conclusion:

In conclusion, the stress and adjustment models addressed in this chapter are comprehensive and sophisticated. Nevertheless, there are several commonalities within the various theories of stress and coping. All of the previous models recognise disability in children as a stressor to family members, which upsets the balance of the family. Therefore, those members have to find ways to adapt to this crisis. In addition, all of the models distinguish factors that might affect the adaptation process (e.g. resources and coping). The adjustment or maladjustment outcomes indicate how successful the adaptation process has been.

These models, however, differ in the factors they specify as mediators/ moderators of the relationship between the crisis and the adjustment outcome. Some of them specify stress-processing factors (cognitive appraisals and coping strategies) as moderators (e.g. the disability-stress-coping model, Wallander et al., 1989; Wallander & Varni, 1992), whereas the transactional stress and coping model hypothesised that coping acts as a mediator between disability or illness and adjustment. Coping and social support play a mediating role in Pealin's model. This indicates a need for more studies to test the mediator/moderator effects of the factors that have an impact on family stress.

The next chapter will discuss in detail research addressing disability as a family crisis and different kinds of mediators and moderators which have been proposed in the literature. I will review how these factors can affect the adaptation process in families of children with ID. In concluding this review, I will establish a model of maternal adjustment to a child with ID drawing on research data and theories reviewed the present chapter.

# CHAPTER 3

# STRESS IN FAMILIES OF CHILDREN WITH DISABILITIES

## 3.1 Introduction:

There is a growing body of research that highlights the experiences of the "whole family members" of children with ID. Researchers have begun to make some methodological advances in family research (Blacher & Hatton, 2001; Hatton & Emerson, 2003). The aim of this chapter is to present a review of the literature about stress in families of children with special needs in general and with ID specifically. This chapter has been divided into six major sections as follows: stress and mental health in parents of children with intellectual disability; initial reactions to the birth of a disabled child; differences in stress and coping between mothers and fathers; variability in parental stress and coping; multicultural issues in stress and coping; and conclusions drawn from  the literature's findings.

## 3.2. Review of stress in parents of children with developmental disabilities:

Recently there has been increased interest in families with members who have developmental disability. Current perspectives on family research have been reviewed (Blacher & Hatton,2001; Hatton & Emerson,2003) and most of these studies pointed to one of the most basic questions that can be asked about such families: Do these families differ from families without a member with developmental disabilities (Koller et al., 1992)?. To answer this question, increased attention has been directed towards the families of children with developmental disabilities. These studies could change the persisting notion that "a family with a child who has a disability is a family with a disability" (Glidden, 1993). Professionals now realize the role that families play in the development of persons with disability (Glidden, 1993).

It is well known that parenting any child is a difficult and challenging task, and one that brings, along with its rewards, varying levels of stress (Gowen, Goldman & Applebaum, 1989). Certainly, raising a child with disabilities involves more challenges than does raising a child without disabilities (Cahil, 1996). Moreover, it creates special difficulties for parents (Byrne & Cunningham, 1985; Dyson, 1997; Glidden & Floyd, 1997). The birth of a child with developmental delays can have adverse effects on family functioning (Waisbern, 1980). Such a child can interrupt the normal life-cycle of the family, leading to a crisis (Molsa & Molsa, 1985), because rearing and caring for the child can be devastating for parents (Gabel, McDowell, & Cerreto, 1983) as it places many extra demands on them (Beresford, 1995). A child with disability can impose more physical, financial, and emotional demands on the parents than children without disability (Kwai-Sang Yau & Tsang, 1999). It is well known that the rate of behavioural and emotional problems is substantially higher in children with intellectual disability than in those without (Dyson, 1997; Einfeld & Aman, 1995; Einfeld & Tong, 1996; Rousy, Best & Blacher, 1992; Tasse & Lacavalier, 2000; Quine & Pahl, 1989) and this may exacerbate difficulties for parents (Rousy, Best, Blacher, 1992). These parents have to spend more time issuing commands and attempting to gain compliance from the child with intellectual disability (Floyd & Philippe, 1993). In addition, parents' pessimism about the child's future (Dyson, 1997), long-term care, additional medical expenses, and the stigma still associated with disabilities are just a few examples of the potential difficulties (Cahill & Glidden, 1996; Fitzegreland, Bulter & Kinsella, 1990).

The impact of having a child with itellectual disability is not limited to the parents, as it can negatively affect the extended family as well (Blacher, et al., 1997; Gabel, Scwartz, &Kotsch, 1981). Parents and grandparents may experience the birth of child with special needs as a psychological crisis (Gabel, Scwartz & Kotsch, 1981; Molsa & Molsa, 1985). Typically Developing siblings of children with disability also experienced difficulties such as denial, shame, fear, disruptive behaviour, psychosomatic pain or tantrums (Molsa & Molsa, 1985). Such a child places a major burden on family relationships (Fitzegrald, Butler, & Kinsella, 1990).

## 3.3 Initial reactions to the birth a disabled child:

The effect on parents of such a critical life event as the birth of a disabled child has been found to change over time and can include emotional and behavioural indicators such as initial shock, disbelief, denial, confusion, sadness, self blame, lowered self-esteem, helplessness, insecurity, social withdrawal, and feelings of being intimidated (Male, 1997). Molsa and Molsa (1985) and Blacher (1984) also confirmed that the immediate reaction includes shock, lack of control, over-protectiveness of the disabled child, rejection of help, and isolation, not only from society but also from family and friends. These parents reported fewer social contacts with friends than did parents of TD children (Seltzer et al., 2001) and they experience a loss of their hopes and aspirations (Seltzer et al., 2001). The first reaction in the families was most often found to be one of denial, grief, and anger (Gabel, Schwartz, & Kotsch, 1981; Molsa & Molsa, 1985). Moreover, a large number of parents experience excessive self-blame and guilt (Blacher, 1984; Deluca & Salerno, 1984; La Borde & Seligman, 1983). Parents feel guilty and responsible for the child's disability even though they clearly know that it is not their fault (Featherstone, 1980; La Borde & Seligman, 1983). Moreover, worry about the child's future (Floyd & Phillippe, 1993; Wing, 1985; Wolf, & Goldberg, 1986) may have an adverse impact on the parents' wellbeing (Wolf et al., 1989).

These impacts of children with special needs on their parents that have been reported in the previous literature (i.e. shock, disbelief, denial, sadness, self-blame, low self-esteem, helplessness, insecurity, social withdrawal, lack of control, rejection of help, isolation, anger, grief, disappointment, and worrying about future, etc) may lead to more serious problems for parents. Two major problems have been reported in previous studies: parental stress and parental mental health problems. There is much evidence that parents of children with developmental disabilities in general and parents of children with intellectual disabilities especially, face higher levels of stress than parents of typically developing children.

### *3.3.1. Stress:*

It is not surprising that higher stress levels have almost always been found in families with children who have disabilities in contrast to families with TD children (Dyson, Edger, & Crinc, 1989; Fredrich & Fredrich, 1981; Scott, Sexton, Thompson, &Wood, 1989; Wilton, & Renaut, 1986). Dyson (1991, 1997) clarified that fathers and mothers of children with disabilities reported significantly greater amounts of parental stress than did parents of children without disabilities. Such families experience heightened parental stress (Dyson & Fewell, 1986; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984; McKinney & Peterson, 1987; Waisbern, 1980).

The literature suggested that families of children with disabilities exhibit variable outcomes compared to the general population especially in terms of parenting stress (Gowen, Johnson-Martin, Goldman, & Applebaum, 1989). With few exceptions, most previous research examining the effects of ID children upon family functioning reported that such families are subject to high levels of stress causing psychological impairment to some, if not all, family members (Byrne & Cunningham, 1985).

Previous research also suggested that parents of children with disabilities experience more caregiving difficulties (Beckman, 1991; Erickson, 1989; Heller et al., 1997; Parke et al., 1995) which might lead to more child-related stress (Boyce et al., 1991; Dyson, 1997; McKinney & Peterson, 1987) than parents of typically developing children. Parents continually pointed out that having a problematic child 365 days of the year exhausted them and caused considerable tension within the home (Fitzegrald, Butler, & Kinsella, 1990). Consequently, parents often report sadness, frustration, and anger (Schilmoeller & Baranowski, 1998). This non-stop tension and the additional demands on parents' time, energy, finances and emotions result in increased feelings of distress (Gowen et al., 1989).

Social scientists generally supported the notion that these mothers and fathers face enormous challenges, including serious symptoms of psychological stress, a terrible sense of loss, a prolonged crisis and lowered self-esteem (Waisbern, 1980). Beresford (1996) mentioned that stress caused directly by the impairment includes meeting the child's physical or medical needs, supervising or watching over the child, and dealing with sleep and behavioural problems. Kwai-Sang Yau & Tsang (1999) mentioned that children with disability adversely affect the family system, as he/she will tend to create more burdens in caregiving and financial expenses, as well as unbalancing the family dynamic and adding to marital strain. Moreover, Fitzegrald, Butler, & Kinsella, (1990) reported that parents found the interference of the disabled child with siblings' rooms, study time and leisure activities also a source of stress. Most of the previous studies indicated that family stress is related to the care of a child with special needs (e.g. Dyson, 1991).

Some authors suggested that parents of exceptional children may also experience general distress that reflects the interrelated nature of their daily stressors (e.g. Forehand, Furey & McMahon, 1984). On the other hand, Cameron and Orr (1989) found that half of their sample of families of children with delayed development had moderate to low levels of stress. Smith (1997), showed that parents of children with disabilities experienced a greater level of stress relating to their children than parents of children without disabilities. Parental stress was associated with aspects of family functioning as perceived by themselves and their spouses. These families always experienced a high degree of stress and a low level of family functioning (Dyson, 1991). These parents were more likely than other parents in comparison groups to experience excessive stress, limited social support, marital dissatisfaction and depression (Beckman, 1983; Friedrich & Friedrich, 1981). Krauss (1993) explained that parental stress refers to the dimensions of a parent's functioning (e.g. depression, sense of competence, relationship with spouse).

Many studies reported that the presence of a disabled child presents a continuous risk of higher stress and increased dysphoria (Singer, Song, Hill, & Jaff, 1990; Waisbern, 1980; Wolf et al., 1989). The dysphoria reported by some parents may be associated with the stress of parenting a difficult child rather than reflecting an actual depressive disorder (Dumas, Wolf, Fisman, & Culligan, 1991).

The stress related to parenting a child with special needs does not only appear with specific kinds of disability, but is a major problem for all families of children with special needs. These include: parents of children with Down's syndrome (e.g. Roach, Orsmond, & Barratt, 1999; Beckman, 1991; Boyce et al., 1991; Rodrigue, Morgan, & Geffken, 1990), parents of children with intellectual disabilities (e.g. Baker, Landen & Kashima, 1991; Blacher, 1984; Crinc, Friedrich, & Greenberg, 1983; Waisbern, 1980; Dyson, 1997), parents of autistic children (e.g. Wolf et al., 1989), parents of children with life-threatening illness (e.g. Mastroyannopoulou et al., 1997), parents of hearing-impaired children (e.g. Schlsinger, 1971, cited in, Vaccari & Marschark, 1997), parents of children with cerebral palsy (Weinhouse et al., 1992), and even parents of children with Attention Deficit Hyperactivity Disorders ADHD (e.g. Pearson et al., 2000).

### 3.3.2. Mental Health Problems (Anxiety- Depression):

This continuous parental stress can cause major or minor mental health problems for parents, such as anxiety and/or depression. As is known, depression is a major health problem, with general population rates for major depressive disorder between 4% and 8%. Certainly, childbearing and childcare may be stressful and thus may pose risks for both initial occurrence and recurrence of depressive episodes (Gelfand, Teti, & Jameson, 1996).

Depression ensues when individuals believe that their helplessness is their own fault, and that they will be helpless for a long time and in a wide range of situations (Meager & Migrom, 1996). Research has shown increased levels of mental and physical health problems among parents of disabled children compared with parents of non-disabled children (e.g. Quine &Pahl, 1986; Beresford, 1996). They indicated that parents of children with disability appear to experience higher levels of stress and depression than other parents (Beckman, 1983; Beckman & Bell, 1981; Hadadian, 1994; Hanson & Hanline, 1990; Kazak & Marvin, 1984; Kwai-Sang Yau & Tsang, 1999; Scott et al., 1989) They have been found to be at hightened risk of depression, stress, (Blacher, 1984; Crinc, et al., 1983), and marital distress (Fredrich & Fredrich, 1981; Waisbern, 1980).

Depressive reactions, especially immediately after diagnosis, are common responses to rearing children with disability (Glidden & Floyd, 1997; Harris & McHale, 1989; Minnes, 1988). Historically, both clinicians and researchers focused on negative family reactions, such as denial, anger, shame, guilt, and depression (Glidden & Floyd, 1997). In George's study (1988) he revealed that these parents may experience reactive depression and lower self-esteem and may have difficulty accepting and relating to the child. Parents of children with special needs lacked confidence in dealing with their child and felt isolated and depressed (Fitzgerland, Bulter & Kinsella, 1990). They face greater parenting stress, greater disruption in their attachment, greater depression and social isolation (Singer et al., 1990). Research has noted that families with developmentally delayed children are perceived to have more family problems and they were more likely to report more vulnerable symptoms of depression (Blacher et al., 1997; Glidden & Floyd, 1997; Hops et al., 1987; Roach et al., 1999; Singer et al., 1999; Seltzer et al., 2001; Wolf et al., 1989 & Zahn-Waxler et al., 1990).

These depressive reactions may significantly impede coping by parents of children with ID (Glidden & Floyd, 1997). Roach et al. (1999) reported that parents of children with Down's syndrome reported significantly more difficulties with perceived competence in parenting, more health problems, greater feelings of role restrictions, and higher levels of parenting depression than did parents of typically developing children. Molsa and

Molsa (1995) showed that where denial was the immediate reaction of both parents when told that their child was mentally disabled, depression followed, which was experienced by most of the parents (70% of mothers and 67% of fathers).

Although depressive reaction was reported as a major mental health problem by most of the parents, anxiety has also been found as a result of parenting a disabled child. Thome & Alder (1999) revealed that the construct of distress related to child-bearing and parenthood is multi-dimensional and can comprise several related but distinct concepts such as parental stress, depressive symptoms, anxiety, and fatigue with its side effects. These parents reported increased levels of mental health problems (i.e. anxiety and depression) compared to parents of TD children (Dumas et al., 1991; Friedrich & Friedrich, 1981; Mash & Johnston, 1983; Mastroyannopoulou et al., 1997; Singer et al., 1999; Waisbren, 1980; Wallander et al., 1989). Moreover, there are many previous studies that focused on the anxiety for one or both of the parents that has been caused by parenting a child with disability (e.g. Byrne & Cunningham, 1998; Molsa & Molsa, 1985; Soliday, McCluskey & O'Brien, 1999; Singer et al., 1999).

## 3.4. Differences in stress and coping between mothers and fathers:

It has been reported that in the general population and in care-giving studies, women report more depressive symptoms than men (Nolen-Hoeksema, 1990; Pruchno & Resch, 1989) and have higher levels of subjective burden (Heller, Hsieh, & Rowitz, 1997; Kramer & Kipins, 1995; Miller & Cafasso, 1992). Overall, women's depression rates are roughly twice or more than twice those reported by men (Goldin & Gershon, 1988), and women represent two thirds of the cases of major depression (Nolen-Hoeksma, 1990).

Studies investigating differences in mothers' and fathers' responses to their child's disability found that women generally respond more emotionally (with anxiety, depression, and concern) compared to men (Affleck, Tennen,

& Rowe, 1990). Mothers of disabled children experienced the intense effects of stress to a significantly greater degree than fathers (Bristol, 1984; Houser, 1987). More specifically, the literature is full of research findings that underscore the impact of a disabled child on mothers (Sonnek, 1986).

Developmental and behavioural difficulties in children have been found to be related to the decrease in a mother's esteem regarding her parenting ability (Bristol & Schopler, 1984; Bugenthal & Shennum, 1984; Kazak & Marvin), increased negative perceptions of her child and elevated anxiety and depression (Friedrich & Friedrich, 1981; Mash & Johnston, 1983; Waisbern, 1980). Fitzegerald and Kinsella (1990) reported that a large percentage of mothers felt that they had suffered major problems overall with their child with special needs. Blacher et al. (1997) showed that mothers reported more family problems, worse health, and more negative feelings about parenting their child with intellectual disabilities. It is obvious that according to the literature, mothers of intellectually disabled children do experience psychological distress (Hobfoll, 1991; Solper, 1996; Sloper & Turner, 1993), and they do experience higher levels of stress (Beckman, 1983; Wishart et al., 1981, Cunningham, 1985; Kazak & Marvin, 1984).

These children with developmental delays were seen as more distractive and less acceptable to mothers (Singer, Hill, & Jaffe, 1990). They respond more emotionally and are more concerned about their ability to cope with the burdens of child care (Seligman et al., 1997). Hence, there are high risks of emotional problems (Friedrich & Friedrich, 1981) and they may be at more risk of psychiatric problems than fathers (McConachie, 1986). Mastroyannopoulou et al. (1997) reported that being a female parent was significantly predictive of higher mental health adjustment difficulties. They reported experiencing more negative impact in a number of areas (Mastroyannopoulou, 1997) such as greater stress symptoms (Beckman, 1991; Golberg et al., 1986; Krauss, 1993, Esex, Seltzer & Krauss, 1999). According to Dunst, Trivette, and Cross (1986), mothers of pre-school children in early intervention programmes reported poorer emotional and physical health than did their husbands.

This is because in families of children with disabilities, the additional childcare burden generally falls to mothers (Byrne & Cunningham, 1985; Heller et al., 1997; Rodrigue, Morgan, & Geffken, 1990). For most children with disabilities, their physical, social, and psychological environment revolves around their family, particularly their mothers (Eheart, 1982). The mother is the one who most frequently takes care of the child at home, takes him/her to medical appointments, and stays in hospital (Havermans & Eiser, 1991; Mastroyannopoulou et al., 1997). Stewart et al. (1994) found that mothers of chronically ill children (spina bifida, diabetes, cystic fibrosis) reported changes in their own health as a result of caregiving. The majority of them stated they lacked the time to meet their own needs, felt isolated, fatigued and lacked respite time to maintain their own health.

They dedicate more time to caregiving and assume relatively more responsibility for child socialization than do fathers (Lamb, 1997; Parke, 1995; Wille, 1995), even when both parents were employed (Menaghan & Parcel, 1990; Shelton, 1990; Tiedje & Darling-Fischer, 1993). Hence, when both the mother and the father of a child with disability were employed, the mother's responsibility for childcare may be particularly striking (Bristol, Gallagher, & Schopler, 1988; Willoughby, & Glidden, 1995). Therefore, many mothers will be forced to abandon their work, adding to their sense of isolation and potentially increasing the likelihood of their experiencing emotional problems (Hobfoll, 1991; Sloper & Turner, 1993), or they may avoid returning to work (Barnett & Boyce, 1995; Mardiros, 1985).

Kwan- Sang-Yau (2002) revealed that parents of disabled children experience a relatively high level of stress, however, mothers had significantly higher stress levels than fathers. Frey, Greenberg and Fewell (1989) showed that because mothers shoulder most responsibility for childcare they may experience child-related stress more than fathers. Seligman et al., (1997) reported that mothers respond more emotionally and are concerned about their ability to cope with the burdens of childcare. They reported more difficulties than fathers in adjusting to the personal aspects of parenting and parenthood (parental health, reactions in roles, and relations with spouse) (Krauss, 1993; Rousy, Best & Blacher, 1992).

Researchers suggested that the parental role of mothers in families of individuals with ID put them at greater risk of dysphoria and strain than fathers (Heller et al., 1997). In addition, mothers with children with disabilities had higher levels of parental stress and depression (Beckman, 1991; Bristol, Gallagher, & Schopler, 1988; Kazak, 1987). Whereas, fathers of children with autism showed typical levels of depression (Bristol & Gallagher, & Schopler, 1988; Veisson, 2000). Nevertheless, Olson and Hwang (2001) suggested that fathers may show their distress in ways other than depression. Or, this effect may be specific on maternal carers and mothers may be more depressed than fathers due to the amount of time spent on additional care demands (Olsson, & Hwang, 2001).

Mothers reported more pessimism regarding their child's future than fathers (Rousy, Best, & Blacher, 1992). They experience more depression and a greater subjective burden of care than fathers (Essex, Seltzer & Krauss, 1999, Bristol et al., 1988; Beckman, 1991; Krauss, 1993). On the other hand, fathers of children with disabilities, when compared to mothers, reported coping very differently (Masrtoyannopoulou, 1997) and they reported different reactions towards their child. Fathers of disabled children experienced no greater stress than fathers of controls (e.g. Kazak & Marvin, 1984). Moreover, Roach, Orsmond, & Barratt (1999) reported no differences between fathers of children with autism and the control group as regards depression symptoms, whereas mothers were more depressed than the control group. Because fathers of children with disabilities were less involved in childcare or housework (Bristol, Gallagher, & Schopler, 1988), they experience lower levels of parental stress (Kazak & Marvin, 1984; Tavormina et al., 1981) and more life satisfaction (Milgram & Artzil, 1988) than mothers. They were less likely to experience adjustment difficulties (Mastroyannopoulou, 1997), even though they received less social support than mothers did (Dyson, 1997) and coping has been found to be less effective among fathers than mothers (Essex, Seltzer, & Krauss, 1999).

With regards to social support, some differences were also reported between mothers and fathers of children with disabilities. Mothers found support from friends and relatives to be most helpful while fathers considered spousal support more important (McLinden, 1990; Crowley & Taylor, 1994).

It is important to differentiate the type of parenting stress experienced by each of the parents rather than only focusing on the level of stress. Krauss (1993) studied parental stress of mothers and fathers of toddlers enrolled in early intervention programmes. Similar parenting-related stress was reported. However, mothers had more difficulty with personal factors such as health, restrictions in role, and relation to their child. Fathers reported more stress related to child characteristics, temperament, and their relationship with the child. In addition, fathers reported more difficulty with attachment to their children than mothers did. Frey, Greenberg and Fewell (1989) reported that higher stress among fathers was strongly associated with gender (having a son) and the lower communication skills of the child. The mother's adjustment was linked to the amount of social support she received.

Some studies found no differences between fathers and mothers with regards to stress level and family functioning (Hagborg, 1989; Spaulding & Morgan, 1986, Dyson, 1997); they also found no differences between fathers and mothers of disabled children and the control group in terms of social support (Dyson, 1997). Hadidian (1994) compared perceived stress and social support in fathers and mothers of children with and without disabilities. There were no reported differences between fathers' and mothers' stress. Dyson (1997) also reported completely opposite results: that fathers experienced more stress and have fewer constructive outlets than mothers.

In general, research has focused mainly on mothers (Beckman, 1991; Bristol, Gallagher & Schopler, 1988; Goldberg et al., 1986). All of these studies have focused only on birth parents, mothers and fathers of naturally conceived children reported significantly higher levels of stress associated with parenting (Golombok et al., 1995). Moreover, the biological mothers experience more depression than adoptive mothers (Glidden & Floyd, 1997). Hence, all of the studies we discuss in this and the following chapters will focus only on biological families and mothers of children with disabilities.

## 3.5. Variability in parenting stress:

Stress is conceptualised not only as a cause and effect but also as a process that is dynamic. Individual stress theories explain how events affect one's morale and functioning, and how individuals can react very differently to similar events (Ezinwanyi, 1999).

Most of the previous findings concentrated on the negative effects that face parents of children with disabilities and especially mothers who reported more stress, depression, and worries or anxiety. In addition, there was a virtual consensus among researchers that most parents experience an increased degree of stress during the course of child-rearing (e.g. Beckman, 1983; Dyson, 1991 & 1993; Dyson, & Fewell, 1986; Fridrich & Fridrich, 1981; Wilton & Renault, 1986). Less agreement about variations in parental stress have been reported (Wishner, 2002). However, some research within families of children with learning disabilities have demonstrated that parental stress fluctuates.

Families, including grandparents and siblings, have both positive and negative experiences of raising their children with disabilities (Clark & Watson, 1988; Diener & Emmons, 1984; Veit & Ware, 1983). Byrne & Cunningham, (1985) reported that although the negative measure of the marital relationship of the parents of children with Down's Syndrome was higher than in the control group, the positive measure was also higher in this group. It is worth mentioning that parents or families with children with disabilities are not a homogeneous group and are therefore likely to show variability in their responses to the event (Kwai-Sang Kwai-Sang Yau & Tsang, 1999). Each family must be considered as individual (Byrne & Cunningham, 1985) because each parent responds in his/her unique way, and these responses must be respected as a reaction unique to that particular parent, and not as a part of a stereotypical process of adaptation (Hanline, 1991).

One should not automatically assume that the family is under debilitating stress when they have a child with a disability. Some families have been able to adapt and cope successfully and keep stress conditions under manageable control (Gallagher et al., 1981, Hastings & Taunt, 2002). In the literature fewer studies reported that these families do not experience greater stress than families of children without disabilities (e.g. Gowen et al., 1989; Harns, & McHale, 1989; Salisbury, 1987; Frey, Greenberg, & Fewel, 1989). Some parents do not necessarily have additional problems in rearing a child with disability compared to parents of TD children (Summers et al., 1989). Furthermore, others appear to adjust quite well and seem to live a normal life (Kwai-Sang Yau & Tsang, 1999). Gowen et al. (1989) reported that mothers of disabled children do not differ on maternal depression and feeling of parenting competence from parents of TD children. Others reported that these families do not experience greater stress (Frey, Greenberg, & Fewell, 1989; Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989; Harris, & McHale, 1989; Salisbury, 1987). Families who have adequate crisis-meeting resources had less stress, greater family harmony, and a stronger feeling of personal reward associated with parenting (Minnes, 1988). These parents have well-being levels similar to their same age peers (Seltzer et al., 2001). Some studies reported that mothers of children with ID report fewer personal and family problems (Friedrich, Wilturner, & Cohen, 1985). Others reported that these families do not experience less marital satisfaction (Kazak, 1987; Kazak & Marvin, 1984). These families were not more likely to display higher rates of coercion and aversion (Floyd & Philippe, 1993). These families (with children with special needs) enjoyed the same level of positive family interactions as do families of TD children (Dyson, 1991).

More recently there has been a growing recognition of the rewards and benefits involved in rearing children with disabilities and the strengths that family members bring to the task (Abbott, & Merdith, 1986; Affleck, Tennen, & Gershman, 1985; Byrne & Cunningham, 1985; Garland, 1993; Heller, 1993; Summer, Behr & Turnbull, 1989). Some researchers began to recognise that many families have positive perceptions of raising a child with disabilities (Summer, Behr & Turnbull, 1989; Hastings & Taunt, 2002). In addition, several researchers described the joy, rewards and other positive effects of having a disabled child (Turnbull & Behr, 1986; Turnbull, 1985).

Current studies indicated that families of children with disabilities, including those whose disabilities are severe, often believe their lives have been enriched by their children's presence (Cunningham, 1982; Fewell, 1986; Turnbull, 1985; Turnbull et al., 1986). Some parents reported that they have acquired more depth and understanding of faith and love, as well as greater tolerance, strength and professional development (Singer & Irvin, 1989; Featherstone, 1980; Turnbull, 1985). Parents of children with disabilities reported closer family ties, improved social networks, opportunities for career development and an increased feeling of personal control (Turnbull et al., 1988). Darling (1987) found that families with disabled children often report increased family cohesion and involvement. They report personal growth for individuals within families. Ferguson and Asch (1989) described parents' experience of personal growth as a result of raising a child with disability. Many parents and siblings are able to maintain normal, or better, morale and to eventually view their family member with developmental disabilities as a positive contributor to the family's quality of life (Nixon & Singer, 1993). The mother-and-disabled child relationship was strengthened (Molsa & Molsa, 1985). Moreover, in a survey of parents by Wilker, Wasow and Hatfield, (1983), three quarters of the sample population felt their experience had made them stronger.

Furthermore, Kearney and Griffin, (2001) reported that the parents of children with disabilities see their experience as being positive.

These studies suggested that families' positive perceptions associated with child disability may help individual members adapt (i.e. cope) (Hasting & Taunt, 2002). These positive perceptions are different outcomes to stress and other negative experiences and may play a central role in the coping process (Hastings & Taunt, 2002). Moreover, they assume that positive perceptions will be present where negative outcomes such as stress are absent or are measured at relatively low levels. Folkman and Moskowitz (2000) and Taylor (1983) reported that positive perceptions may help us to cope with traumatic and stressful events. Such positive affect may act as a buffer against the adverse psychological consequences of stress, and help to protect against clinical depression (Folkman & Moskowitz, 2000; Folkman, 1997; Hastings & Taunt, 2002).

Families of children with disabilities do not seem to report fewer positive perceptions (Hastings & Taunt, 2002). However, there are some features of families that adapt well to their crisis. For example, Dulan (1998) suggested that the positive outlook associated with religious and spiritual belief help carers meet the challenges of life with positive self-talk that limits being overwhelmed by their circumstances. Some researchers (Varni, Katz, Colegrove & Dolgin, 1996; Varni & Wallander, 1988) described a multivariate conceptual model of adjustment involving risk and resilience factors. Risk factors include disease parameters, functional ability, and time since diagnoses. Resilience factors are categorised as follows: (1) interpersonal factors such as temperament; (2.) socio-economic factors such as family environment, social support, and economic status, (3) stress processing factors, such as the coping strategies used (Mastroyannopoulou et al., 1997). These theories emphasised the importance of multiple variables that can lead to substantial differences between families.

Finally, we believe that, although no-one's life is stress free, the demands upon some people are greater than those on others. Moreover, disability alone does not cause problems in parental well-being. However, there are factors added to disability which increase or decrease family stress in general and mothers' stress in particular.

In the next section of this chapter, the most important characteristics that enable some families to adapt better than others will be summarised. These include coping strategies used by the family; personal resources of the mothers and characteristics of the disabled child. Characteristics of the family and social resources that are available to the family are the most important factors which may differ from one family to another.

## 3.6. Factors that enhance parental adjustment and adaptation:

"Why some families are better able to negotiate their way through transitions and tragedies and to cope with and even thrive on life's hardships, while other families, faced with similar if not identical stressors of family transitions, give up or are exhausted" (McCubbin & McCubbin, 1987, p.3). Some of the factors that enhance parental adjustment as reported in the previous studies will be addressed.

### *3.6.1. Coping Boosters:*

Lazarus and Folkman (1984) defined coping as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised to be taxing or exceeding the resources of the person' (p.141). Turnbull et al. (1986) defined coping as any resource to reduce the family's distress. The coping behaviours can be motivators to change the situation or change the perceived meaning of the situation. Coping has been seen as the natural counterpart to stress (Lazars & Folkman, 1984). They considered coping as a protective factor with its absence considered to be a risk factor (Lazarus & Folkman, 1984). In this section, I will discuss in some detail the coping strategies, coping resources, coping styles, and coping responses that have been reported in the literature.

In the literature, there were different kinds of strategies that focus on the reduction of distress which included avoidance, minimization, distancing, selective attention, social comparison, or looking at the positive aspect of the situation (Folkman et al., 1991). However, we will focus on the main two coping strategies addressed in Lazarus and Folkman (1984) study, which are problem-focused and emotion-focused coping.

**3.6.1.1. Problem-focused coping:** the problem-focused form, whether directed at the environment or at the self, serves to assist the individual in managing stressful demands in situations that are viewed as 'capable to change' (Lazarus & Folkman, 1984). In other words, it usually occurs when the conditions are appraised as agreeable for change (Lazarus, 1999). Problem-focused coping strategies are also called 'active' strategies (e.g. information-seeking). These form of coping strategies can also include interpersonal conflict resolution, information gathering, advice seeking, time management, and goal setting (Folkman et al., 1991)

**3.6.1.2. Emotion-focused coping:** regulates the emotions tied to the stressful situation without changing the situation (Lazarus, 1999). This strategies are also called 'Passive' strategies. We use these more often when the stressors are perceived as uncontrollable (Lazarus & Folkman, 1984). Emotion-focused strategies are more likely to be used in situations such as cognitive reappraisals where nothing can be done to modify the problematic circumstances, and might be helpful in mitigating the effects of stress (Dyson, 1997).

In terms of coping styles, there are no universal effective or ineffective coping strategies. Rather, the effectiveness of a strategy depends on the type of person, the type of threat, the stage of stressful encounter, and the desired outcome (Lazarus, 1999). Beresford (1996) indicated that parents can use the coping strategies that they find work best for them. However, other studies (Billing & Moos, 1981; Billing & Moos, 1984; Essex, Seltzer, & Krauss, 1999; Kramer, 1997; Lutzky & Knight, 1994) reported that in general, for both parents, emotion-focused coping is associated with higher levels of psychological distress, whereas problem-focused coping is associated with lower levels of distress. Likewise, Frey, Greenberg and Fewell (1989) showed that a problem-focused coping style was related to lower levels of psychological distress, while avoidance, self-blame, and wishful thinking were associated with higher distress. A study by Essex, Seltzer & Krauss (1999) showed that there were no differences between mothers and fathers with respect to their frequency of use of emotion-focused coping; however, mothers used significantly more problem-focused coping strategies than did the fathers (Essex, Seltzer, & Krauss, 1999). Conversely, Ptacek, Smith and Dodge (1994), Thoits (1995) and Vingerhoets and Van Heck, (1990) reported that women were less likely than men to use problem-focused coping and more likely to engage in emotion-focused coping. Results also showed that for mothers, greater use of problem-focused coping strategies and less use of emotion-focused coping buffered the impact of caregiving stress on their psychological well-being. On the other hand, for fathers no buffering effects of coping were detected (Essex, Seltzer, & Krauss, 1999). In the study conducted by Mallow and Bechtel (1999) on the chronic sorrow experience of parents of children with developmentally disabilities, it was found that the parents tended to rely primarily on problem-solving coping strategies, which included seeking more information about the child's illness and seeking support from family and friends.

Lazarus and Folkman (1984) outlined six types of coping resource:

1. Parental health and energy which involve their physical and emotional well-being prior to and during the course of a stressful event. Parents who are sick, tired, or exhausted have less energy to spend on coping than healthy parent.
2. Problem-solving skills, which may include strategies that parents utilize to cope with the chronic stressors. Coping strategies include problem-focused, emotion-focused and avoidance processes.

3. Social support, which involves a potentially supportive relationship, may facilitate positive adaptation.
4. Material resources, which include factors such as socio-economic status and income.
5. Positive beliefs include person-related variables such as the individual's feeling of self-efficacy, greater internal locus of control, and beliefs in some higher purpose (e.g. religious faith).
6. Social skills, which refers to the ability to communicate with others in socially appropriate and effective ways (Lazarus & Folkman, 1984).

Every family or parent is an individual and unique in their personal and social resources. Obviously, they will employ various strategies to cope and manage stress "appropriate" to their situations (Kwai-Sang Yau & Tsang, 1999).

In coping with threat, Zuuren and Dooper (1999) reported two important styles. The first style concerns the degree to which an individual cognitively confronts him or herself with the upcoming threat; the second style pertains to the degree to which an individual makes use of cognitive avoidance. These styles have been named "monitoring" and "blunting" respectively, and they have often been shown to be independent of each other (Zuuren & Dooper, 1999). It is not clear which style of coping is better or worse in the long term (Mastroyannopoulou et al., 1997).

Pearlin and Schooler (Mahan & Shaughnessy, 1999) suggested that coping responses fall into three categories: responses that directly change the problem or situation from which the stress ensues; responses that alter the meaning of the situation or reinterpret the problem, and those that manage the emotional distress provoked by the problem. Coping resources were also mentioned in the literature, and they can be considered as risk or protective factors and may lead to resilience in the face of adversity (Rutter & Garmezy, 1983). According to Folkman et al. (Byrne & Cunningham, 1985) the resources available to people in developing their coping repertoires include health, problem-solving skills, utilitarian resources, social support, and general and specific beliefs. Folkman, Shcaefer and Lazarus pointed out that potential resources include the health and energy of individual family members, their problem-solving skills, perceptions and definitions of their situation, relationship with the family, and the family support networks (Byrne & Cunningham, 1985). Their model highlights conscious, purposive cognitions or behaviour (Mahan & Shaughnessy, 1999; Folkman, 1991; Lazarus, 1992). Many studies' results about parenting stress strongly supported the utility of the proposed multidimensional model of Lazarus and Folkman. They emphasised the importance of coping strategies and coping resources in reducing the adverse effect of stress (e.g. Beresford, 1996; Essex, Seltzer & Krauss, 1999; Frey, Greenberg, & Fewell, 1989; Mahan & Shaughnessy, 1999). This idea has been adopted in this study's model as well.

It is obvious that for some parents having a disabled child was not the main cause of stress (Beresford, 1996). It is important to realise which coping strategies have been used by those parents. Coping refers to the "person's cognitive and behavioural efforts to manage (reduce, minimize, master, or tolerate) the internal and external demands of the person-environment interaction that is appraised as taxing or exceeding the person's resources" (Gruen & Delongis, p. 572). Coping refers to any attempts to deal with stress, whether or not it is successful or effective (Beresford, 1996). Frey, Greenberg and Fewell, (1989) reported that positive self-appraisal of coping skill was related significantly in reducing parental stress to better family adjustment, and reducing psychological distress for parents of young children with disabilities. It was also reported that ability to cope was not found to be related to depression (Schereus, DeRidder & Bensing, 1999). It may take from a few months to several years to cope, and some parents may always remain in a particular stage without being able to achieve the transition to the adaptive stage (Molsa & Molsa, 1985). Past research showed that over time individuals gain experience in coping with problems (Kling et al., 1997).

### 3.6.2. Personal resources:

Personal resources in parents include personality, self-appraisal, educational level, financial status, problem-solving skills and so forth. It appears that there is no universal personal reaction to the added stress of raising a child with disabilities (Kwai-Sang Yau & Tsang, 1999). Parents who were well adjusted before having the disabled child have a better chance of coping with the situation than those who were already having psychological problems (Hallahan & Kufman, 1991). Byrne and Cunningham (1985) reported that mothers who felt their social and leisure activities were restricted, who were unhappy with their roles as housewife or mother and who felt that they did not receive sufficient help, also experienced more stress.

***3.6.2.1. Maternal age:*** The age of the mother is an important personal resource. Data suggested a negative correlation between age at marriage and maternal stress with younger mothers reporting higher levels of stress than older mothers (Boyce et al., 1991; Cogner, McCarthy, Lahey & Kropp, 1984; Macis et al, 2001; Ostberg & Hagekul, 2000). In addition, it has been reported that a younger mother may inappropriately attribute difficulties in coping (Meager & Migrom, 1996). Birkel and Rupucci (1983) found that younger parents always drop from the parent education group. Gelfand, Teti and Jameson (1996), Gotlib et al. (1989); and Weissman and Boyd (1983) strongly emphasised that mothers who are particularly susceptible to depression are younger, less educated, have a greater number of children at home, have experienced recent negative life-events, bad relationship with spouse, and describe themselves as housewives. Magana (1999) also reported that the younger age of the mother is associated with burden and stress.

This finding has been replicated with different ethnic groups (Cogner et al., 1984) as well as with children who have different types of disabilities (Boyce et al,. 1991, Macias et al., 2001).

Most studies found negative correlations between maternal age and parenting stress. There is limited evidence suggesting a positive relation (e.g Ostberg & Hgekull, 2000; Hellerl & Factor, 1993). A study of school-age children yields different results showing that older mothers experienced more stress than younger mothers (Ostberg & Hgekull, 2000). Hellerl and Factor, (1993) reported that older parents reported more care-giving burden than younger parents.

While some of the studies found a positive relationship between maternal age and parenting stress, most of the studies supported a negative effect. This might be because of the level of support received by mothers. Turner and Mario (1994) reported that the lowest level of support were found among ages 18-25, while the highest levels were found in 35 to 45 age group.

***3.6.2.2. Level of education*:** Education has a positive relation to parenting stress. Parents with higher levels of education are able to cope more effectively with their child's disability than parents with less education (Barber et al., 1988). Because educational level is usually associated with socio-economic status, it is one of the family characteristics that is found to influence parental coping (Kwai-Sang Yau & Tsang, 1999). Palfrey et al. (1989) reported that the higher the mother's educational level, the more likely it was that the stress related to the child's disability rather than to parental functioning. Singer et al. (1990) reported that better educated mothers who were of higher socio-economic status perceived their children as less demanding and distructive. On the other hand, less educated mothers rated their children as more demanding (Singer et al., 1990). Magana (1999) also reported that the poorly educated mothers perceive a heavy burden but do not have significant symptoms of depression.

***3.6.2.3.Spousal relationship:*** The stress of having a developmentally disabled child affects the marital unit, marital harmony and marital satisfaction (Gill, 1990). A strong spousal relationship has also been reported in the literature as one of the most important characteristics of the parents that make their reaction different from others'. Its is obvious that mothers' and fathers' stress levels directly and indirectly mutually impact their relationships (Lavee, Sharlin, & Katz, 1996) and their relationship with their children (Erel & Burman, 1995; Floyd & Zmich, 1991; Russell, 1997). Furthermore, it has been assumed that having an ID child will place greater strain upon the parents' marital relationship and it is possible that marital satisfaction may decrease disproportionately over time in families of children with ID (Byrne & Cunningham, 1985). These parents experienced significantly less marital satisfaction than parents of TD children (Friedrich & Friedrich, 1981). Gowen et al. (1989) found that mothers who are suffering from feelings of depression and lower self-efficacy as a parent may view the quality of their family relationship less favourably.

Some studies found no differences in parents of children with special needs, with some experiencing in some measure higher levels of marital satisfaction than control group parents, they overlapped more than the control parents (Kazak & Marvin, 1984). However, some parents, especially those with strong marriages and adequate personality strength, are able to adjust to the challenges of raising a child with disability and maintain a high level of family strength (Abbott & Meredith, 1986; Longo & Bond, 1984; Kwai-Sang Yau & Tsang, 1999). Kwai-Sang Yau and Tsang (1999) reported that parents who are educated, have a strong marital relationship, and are well adjusted personality prior to the birth of the child seem to adjust successfully. Mothers whose spouses had a more positive view of their child become more positive themselves (Frey et al., 1989). Spousal support has been seen as one of the important resources used to cope with challenges in rearing a disabled child (Abbott & Meredith, 1986; Kwai-Sang Yau & Tsang, 1999). The mother's perception of the quality of her relationships with her husband and parents was more strongly associated with her feelings of depression and parenting competence (Gowen et al., 1989).

Marital satisfaction is a key variable in determining the family susceptibility to disorganisation due to the presence of a child with intellectual disabilities and the best predictor of the coping success of mothers of such children was security and satisfaction with marriage (Kwai-Sang Yau & Tsang, 1999). The spouse's coping efficacy was most closely related to family adjustment (Frey, Greenberg, & Fewell, 1989).

***3.6.2.4. Parent-Child relationship:*** The parent-child relationship has been viewed as another important personal resource for parents. It has been found that depressive symptoms in parents are associated with parent-child relationship variables and the child's functioning (Soliday, McCluskey & O'Brien 1999). Parent-child relationship in the case of disabled children has been reported in the literature as an important factor in parents' adjustment and mental health (Bigras, Lafreniere & Dumas, 1996; Epsten, 1987; Blacher et al., 1997; Gelfand, Teti & Jameson, 1996; George, 1988; Hecht, Levine & Mastergeorge, 1993).

Gelfand and Teti (1990) reported that depression is associated with undesirable parenting practices that lead to difficulties in parent-child interaction. Therefore, parenting depression might heighten the child's risk of depression (Hammen, 1991). Consequently, parents' satisfaction with their parent-child relationship may lead to better marital and child adjustment and decrease depression (Gelfand, Teti & Jameson, 1996; Soliday, McCluskey & O'Brien, 1999).

**3.6.2.5. Maternal employment:** the presence of a child with disability in a family has been shown to decrease the number of social activities of the family (Breslau, 1983) and may change parental occupational status. Mothers are still the primary carers for children with disabilities (Ballard et al., 1997; Hoare et al., 1998; Kazak & Marvin, 1984; Krauss, 1993; Lillie, 1993; Stalker, 1996). These mothers are facing the tasks involved in caring for the child with disability in addition to their other family responsibilities (Calgary, 1999). As a result, mothers of children with disabilities rarely assume responsibility outside of childcare, even if they have been active in work prior the birth of the child (Ezinwanyi, 1999). Mardiros (1985) showed that 68% of mothers of moderately to profoundly disabled children had originally planned to return to work after the birth of their children, but only 8% actually did.

There is inconclusive evidence documenting a significant association between maternal employment and parenting stress. There is limited empirical support for the hypothesis that employment outside the home increases parenting stress. The results of a study by McDonald, Poertner and Pierpont (1999) indicated that mothers who work outside the home (full or part time) experience higher levels of stress than mothers who are not employed outside the home. Crockenberg,(1988) mentioned that the relation between maternal employment and the substantial benefits for mothers may be mediated by the effects of job satisfaction and spousal support.

In contrast the results of other studies suggested that maternal employment decreases parenting stress. Gray (1997) and McBride (1989) indicated that although mothers are usually viewed as the primary carers, their researches have shown that the lack of employment can impact both mothers and fathers who spouse is employed. Forgays and Forgays (1993) found that employed mothers of toddlers experienced lower levels of stress than mothers who were not employed. They claimed that mothers who are not employed rely heavily on their child's development as the foundation for their self-esteem. On the other hand, working mothers are able to utilize their status from their multiple roles (i.e. motherhood and job success) as sources of their self-esteem. Markus (1990) suggested that employed mothers of preschool-aged children manifest few symptoms of stress, including less depression, and higher levels of psychological well-being than unemployed mothers.

Warfield (2001) found that becoming employed and maintaining employment may place an extra burden on mothers of children with disabilities. However his recent finding indicated that mothers who were employed full-time reported similar levels of stress to mothers who were employed part-time or who were not employed, because there were no differences in child demands, family support or stress from maternal employment position. Although employment did not seem to increase parenting stress, indirect effects of work can lead to increased burdens (Warfield, 2001).

**3.6.2.6. Marital status:** The evidence concerning the association between marital status and maternal stress is limited. Presence of both parents in the home is usually related to less stress and better adjustment. Conger et al. (1984) addressed marital status as a potential contributor to parenting stress. They suggested that single mothers experienced more stress than married mothers. Beckman (1983) found that single mothers of disabled children, without intimate support from a spouse reported considerably more stress than married mothers of children with a disability. Beckman (1989) concluded that the only demographic characteristics associated with the amount of stress experienced by mothers was the number of parents in the home, with single mothers experiencing more stress. Also other studies noted that being a single parent may be associated with increased levels of stress (Beckman, 1983; Salisbury, 1987, McCubbin et al., 1983; Dumas et al., 1991). In a study of children with spina bifida, (Gill,1990) single mothers of children with spina bifida reported the most distress and the least role satisfaction in comparison to married mothers. The levels of stress reported by mothers were significantly reduced when two parents were present in the home (Beckman, 1983; German & Maisto, 1982). Moreover, married individuals reported more support than unmarried individuals (Turner & Marino, 1994).

### 3.6.3. Characteristics of the disabled child:

The gender, age, behavioural disorders, severity of disability, and type of disability might be the most important characteristics of the child to increase or decrease the level of parenting stress and coping. Studies suggest an association between dysfunctional parenting and depression or social isolation in the context of characteristics of the child such as gender, temperament or personality (Bigras, Lafreniere, & Dumas 1996). However, it is not clear whether there are differences in the amount and type of stress experienced by parents of disabled children and, if so, whether such differences are related to the child's age or gender (Dumas et al., 1991).

***3.6.3.1.Gender:*** In general more boys than girls are intellectually disabled and particularly mildly disabled (Richardson, Karz & Koller, 1986). Moreover, both educational disability and behavioural disturbance have been shown to occur with greater frequency among boys than girls (Richardson, Karz & Koller, 1986). In addition, preschool boys tend to be more overactive than preschool girls (Epsten, 1987; Richman, Stevenson & Graham, 1982), and more boys than girls have psychiatric disorders (Richardson, Karz & Koller, 1986). Korn (1984) and Patterson, (1980) found disabled boys to be more stressful than girls. In general, parents of girls were better adjusted and less stressed than parents of boys (Turnbull et al., 1986, Kwai-Sang yau & Tsang, 1999).

Some studies found that fathers were affected by the sex of the child more than mothers; they may have difficulty adjusting their expectations in relation to their sons (e.g. Frey, Greenberg & Fewell, 1989). Wishner (2002) found that parents of boys experienced significantly more stress than parents of girls. Others found that the child's gender is an important influence on parental adjustment, for mothers in particular (Frey et al., 1989). And some reported no major effect of the child gender on parents (Dumas et al., 1991; Dyson, 1993; Hagborg, 1989; Honig & Winger, 1997; Trute, 1990); they reported that the importance of the child's age and gender in this area is unclear.

***3.6.3.2. Age:*** Some evidence suggested that younger children may be more stressful for parents than older children (Mash & Johnston, 1983), but others reported that older children are more stressful (Bristol & Schopler, 1984; Gallagher, Beckman & Cross, 1983), or found no differences (Beckman, 1991; Byrne & Cunningham, 1985; Dumas, Fisman & Culligan, 1991; Dyson, 1993).

Many studies reported that families of older children show better adjustment and less stress than those with younger children. Fitzgerald, Butler and Kinsella (1990) clarified that most parents experience greater stress during the first four or five years of a child's life, and when appropriate schooling becomes available, the level of stress experienced by parents is reduced. On the other hand, Orr, Cameron, Dobson and Day (1993) reported that parenting stress remains low in early childhood, peaks in middle childhood, and declines in adolescence. Mastroyannopoulou et al. (1997), confirmed that the first two years are likely to be incredibly demanding and challenging to one's roles and expectation of parenthood. The shorter the length of time since diagnosis, the higher the adjustment difficulties in parents. Wolf, Fisman and Culligan (1991) revealed that mothers of younger autistic children reported greater dysphoria. They reported that one of their greatest problems is finding enough time for themselves (Gowen & Schoen, 1985). Pearson et al. (2000) noted that in children with Attention Deficit/Hyperactivity Disorder (AD/HD) and ID, behavioural problems decrease with age. Scherman et al. (1995) clarified that the stress is related to knowing about having a child with disability, but as the child grew older, this no longer remains an issue.

On the other hand, some studies reported more stress in families who have older children. Miller and Sollie (1980) in a study which included infants during their first year of life, revealed that maternal stress increased significantly from one to eight months. Moreover, mothers of three-year-olds experienced higher levels of stress than mothers of two-year-olds (Esdail & Greenwood, 1995). Bristol and Schopler (1984) found that higher levels of parental stress and depression are associated with older children and coping with the child's disability can be more difficult as the child gets older (Sueltze & Keenan, 1981). The adulthood period is reported to be very stressful for parents. Families with disabled teenage children or children entering adulthood experienced more stress than did families who have younger children (Black, Molaison & Smull, 1990; Konac & Warren, 1984; Wikler, 1981; Wikler, 1986). This may be due to the findings that older offspring with ID were found to use fewer services than their younger counterparts (Smith, 1997). Also parents receive less support from formal and informal networks than parents of younger children (Byrne & Cunningham, 1985; Suelze & Keenan, 1981) even though support seems to be more important as children grow older (Dunst, Trivette & Cross, 1986). Family stress during this period can result from a number of sources (Dyson, 1997).

***3.6.3.3. Severity of disability:*** The severity and nature of a child's intellectual disability according to some studies are not related to reported levels of stress (Beckman, 1983; Byrne & Cunningham, 1985). Also, Trute and Hauch (1988a, 1988b) concluded that positive adaptation to the birth of a child with developmental disability by families is unrelated to the severity of the child's disability. Singer et al., (1990) reported that greater severity of child medical and social risk was not related to higher parental stress. However, other studies reported that, according to the distribution levels of ID (mild, moderate, severe and profound) (Tasse & Lacavalier, 2000), the more severe the child's disability, the more stress and less adjustment is reported by parents. Frey et al. (1989) found that greater parental adjustment difficulties were associated with a linear increase in the severity of the child's communication impairment. Along with Frey et al., Greenberg and Fewell, (1989) indicated that parents reported more stress when their child's level of communication skill was relatively low. Orr, Cameron and Day (1991) found that the more severe a child's behavioural problems, the greater the degree of parental stress.

Undoubtedly, parenting a child with severe developmental disabilities poses a number of extraordinary challenges to parents (Nixon & Singer, 1993). They may seek more medical advice (Sonuga-Barke, Thompson, & Balding, 1993) than parents of children with mild disability. Risk factors found to be associated with burden in studies of mothers who care for a child with ID include poor physical health and younger age of the mother and more severe disability (Magana,1999). Hallahan and Kaufman (1991) summarised that parents' psychological make-up depends on the severity of the child's disability, and the amount of support the parents receive from others.

***3.6.3.4. Type of disability:*** The type of children's disability, such as Down's Syndrome, autism, motor disabilities and so on, does affect parents' adjustment. Many studies focused on children with Down's Syndrome who are no less well-adjusted than comparable parents of children without disabilities (Van Riper, Ryff & Pridham, 1992). Mothers of children with Down's syndrome did not differ from mothers of non-disabled children (Dumas et al., 1991). This is because children with Down's Syndrome have been said to be easier to raise than children with other disabilities (Hodapp, 1997; Goldberg et al., 1986) and they cause fewer negative effects on family and individual functioning in comparison to children with other forms of developmental disability (Weinhouse & Nelson, 1992). These parents request institutional care for their children less often than the other parents do (Cahill & Glidden, 1996). Parents of children with Down's Syndrome have exhibited signs, of healthier personal and familial adjustment. Dumas et al. (1991) confirmed that children with Down's Syndrome did not differ from non-disabled children in terms of the parent's measured stress and depression. They have been found to be less stressed and depressed than parents of children with autism (Fisman, Wolf & Noh, 1989; Wolf, Fisman & Noh, 1989). Moreover, mothers of children with Down's Syndrome are less depressed than mothers of children with other forms of intellectual disabilities or with psychotic symptoms (Ryde-Brandt, 1991). Lower anxiety levels and lower rates of anxiety disorders have been reported in mothers of children with Down's Syndrome when compared to mothers of children with autism (Piven et al., 1991; Rodrigue, Morgan & Geffken, 1990; Ryde-Brandt, 1991). Research also suggested that children with Down's Syndrome may be easier for parents than children with autism (Dumas, Wolf, Fisman & Cullighan, 1991; Kasari & Sigman, 1997). As a result, these parents are better-adjusted (Pivent et al., 1991) and have reported greater marital satisfaction than parents of autistic children (Fisman et al., 1989; Rodrigue et al., 1990).

All of the studies looking at families of children with autism report that these families experience more stress and adjustment problems than families of children with Down's Syndrome. Many studies reported that parents of children with autism experience significantly higher levels of parental stress and dysphoria than parents of children with Down's Syndrome and with TD children (Bristol & Schopler, 1983; Dumas et al., 1991; Wolf et al., 1989). The high level of dysphoria experienced by mothers is related to parenting exceptional children rather than to personal dysfunction (Dumas et al., 1991). In addition, mothers but not fathers, of children with autism described themselves as mildly depressed in comparison to mothers of children with Down's Syndrome and with TD children (Dumas et al., 1991). This may occur more when their children are younger. Also, the differences in stress have been noted as a function of the age of children with autism (Donovan, 1988).

Other disabilities have also been found to be more stressful for parents than Down's Syndrome. Marcovitch et al. (1987) revealed that mothers found children with neurological problems and developmental delays of unknown origin more difficult than children with Down's Syndrome. Parents of children with health impairment or with cerebral palsy perceived their children's physical limitations, dependency, and cognitive impairments as significantly more serious than parents of children with Down's Syndrome (Weinhouse et al., 1992). Cahill and Glidden (1996) reported that it is perhaps not that children with Down's Syndrome are much easier to raise than children with other developmental disabilities, but that children with autism are more difficult due to symptoms specific to that disability. Another reason is that parents of children with Down's Syndrome tend to be older than other parents. Hence, the family income may be greater, reducing financial stress, which is common in younger families.

Although, most of the previous studies focused on the differences between children with Down's Syndrome and with other disabilities, and on the psychological reactions in their families, few reported no significant differences between them. In terms of behavioural problems, children with

Down's Syndrome were as different from their siblings without disabilities as children with other forms of Intellectual Disability were from their siblings (Gath & Gumley, 1986a). Hanson and Hanson (1990) found that when families of young children with Down's Syndrome, hearing impairments, and neurological impairments were compared, very few differences were found in the level of maternal stress, satisfaction with parenting, attachment to the child, and interaction with the child. Dumas et al. (1991) noted that although behavioural difficulties usually are not a primary concern for parents of children with Down's Syndrome, those parents are often put under stress by frequent medical and educational concerns. These parents of children with Down's Syndrome, like parents of children with other disabilities, face challenges that may profoundly affect their family's adaptation to their situation (Cahill & Glidden, 1996; Lamb & Billings, 1997).

***3.6.3.5. Behavioural Disorders:*** Characteristics of the child's behavioural problems have also been found to be related to the outcome for parents. Childhood problem behaviours have been classified into those which involve disobedience, aggression, and attention seeking, and personality problems such as fear, shyness, and anxiety (Epstein, 1987). Other characteristics of ID infants such as their social responsiveness, temperament, repetitive behavioural patterns and additional or unusual caring demands were related to parental stress (Beckman, 1983). Individual characteristics of the child and parent can be sources of stress in parenting (Bigras, Lafreniere & Dumas, 1996). As reported in the literature, children with disabilities are more likely to have behavioural and sleep problems (Crinc et al., 2004; Quine & Pahl, 1989). They have limited social/interpersonal skills (D'Zurrilla & Nezu, 1980; Edeh & Hickson, 2002) and they are also susceptible to the full range of mental health problems (Reiss, 1994). It has been reported that maternal psychological status has been found to correlate with childhood emotion and well-being (Singer et al., 1999).

Mothers of infants with difficult temperaments had lower scores for well-being and feelings of competence, and higher scores for distress, whether the infant was disabled (Beckman, 1983) or not (Levitt, Weber, & Clak, 1986). A child who is of overactive or under-active temperament and has, physical disabilities or developmental delays might also increase parental stress (Breen & Barkley, 1988; Goldberg et al., 1990). Depression may be a significant factor contributing to a mother's reported incidence of behaviour problems in children with chronic disorders such as diabetes, cystic fibrosis and ID (Walker et al., 1989). Blacher et al. (1997); Richman, Stevenson and Graham, (1982) and Griest et al. (1980) also demonstrated that mothers of children with a clinically high level of BD are thought to be at a relatively high risk of developing minor depressive disorders compared to control mothers.

These findings clearly showed that childhood behavioural problems are a source of parental stress consistent among all age groups, from toddlers (Creasy & Jarvis, 1994) to preschoolers (Hauser-Cram, Warfield, Shonkoff & Krauss, 2001) to school-age children (Mouton & Tuma, 1988).

### 3.6.4. Characteristics of the family:

The number of children, the socio-economic status, the education level of parents, stigma and attitudes in the community and religion seem to be the most important family characteristics affecting the level of parental stress and coping. The literature reported that the psychological well-being of the parent does not relate only to the presence of a child with disability, but there are also other characteristics of families who adapt well and of others who do not. Ferguson and Watt (1980) found that stress was not related to the presence of an ID child, but was more closely related to social class. They concluded that mothers of disabled children, whatever their social class, are no more stressed and anxious than working class mothers of non-disabled children. Flynt and Wood (1989) also found that there were significant differences due to race and maternal age with regard to perceived stress, as well as differences due to marital status and socio-economic status in relation to coping behaviour. Kwai-Sang Yau and Tsang, (1999) reported that two-parent families with only a few children, high socio-economic status, having adequate crisis-meeting resources, and living in a supportive community appear to be associated with the ability to cope with the stress successfully. Also, in studies of maternal depressive symptoms, researchers found single marital status, poorer physical health, and lower education of the mother along with child maladaptive behaviour to be risk factors associated with more depressive symptoms (Blacher et al., 1997; Greenberg et al., 1997; Seltzer et al., 1995). The other characteristics include family size and form, cultural background (ethnicity), and geographic location of the family. (Kwai-Sang Yau & Tsang, 1999).

***3.6.4.1. Number of children:*** For typically developing children, it is clear that mothers experience higher levels of stress when there are more people (children or adults) in the household (Wishner, 2002). The more children in the family, the greater the level of maternal stress (Ostberg & Hagekull, 2000).

Similarly, in families with disabled children, multiple births may be related to more stress in parents (Singer et al., 1999; Kwai-Sang Yau & Tsang, 1999) and a large number of children may be a strong reason for mothers to think seriously of out-of-home placement for the child with disability (Hanneman & Blacher, 1998). However, Wishner (2002), believed that the stress related to there being more children and adults in the household can only be relevant to families of typically developed children. In contrast, some studies reported that additional adults in the household provide a social support system that is available to assist with caring for the child with ID and the emotional needs by mothers (Wishner, 2002).

***3.6.4.2. Socio-economic status:*** Socio-economic status is reported to be one of the most important family characteristics that might predict the level of stress in parents. Financial concerns have been identified as the overriding family problem (Black, Molaison, & Smull, 1990). In general, reviews of stress associated with families with children who have developmental disabilities, the responses of parents in different socio-economic categories were contradictory (Minnes, 1988b). Studies of families with more limited socio-economic resources reported high levels of stress (e.g. Dunst, Trivette & Cross, 1986; Friedrich & Friedrich, 1981; Hatton & Emerson, 2004; Kazak & Marvin, 1984) and there were robust association between low socio-economic status and child emotional disorders (Hatton & Emerson, 2004). Dyson (1991) generally found that in groups with middle socio-economic status, caring for a child with disabilities is associated with parental stress.

A high level of depression was also related to low socio-economic status. As is known, women are more than twice as likely to be depressed as men (Nolen-Hoeksema, 1990) and this gender difference is well established among lower socio-economic status groups (Robins et al., 1984). Brown and Harris (cited in Epstein, 1987) reported that working class mothers of children have been found to be four times as likely to become depressed than their middle-class counterparts. Singer et al., (1990) stressed that lower social class would be expected to be associated with increased maternal depression and stress.

Blacher et al. (1997) surprisingly reported completely contrary findings. They found that depressed mothers did not differ from non-depressed ones in terms of coping styles, strength of religious belief, or positive perceptions of their child, nor demographic variables of incomes, education, age, language use, employment, or country of origin. In addition, Byrne and Cunningham, (1985) reported that parental age, socio-economic status and family size do not appear to contribute significantly when predicting the amount of stress reported in families of disabled children.

***3.6.4.3.Attitudes and stigma:*** although people are becoming more educated regarding the aetiology of mental disorders, still the presence of pervasive stigma, discrimination, and misunderstanding has been reported (Hall, 1999). Some parents found the reactions to their child from members of their family and the public to be very distressing (Beresford, 1996). Over 70% of carers indicated that most people hold stereotyped and negative attitudes towards people with serious mental disorders and sometimes treat them in an offensive, rejecting, and reactive manner (Struening et al., 1995).

To sum up, Stigma in communities have also been reported to be related to parental stress and it places an extra burden on family members (Wilson, 2002).

***3.6.4.4.Religion:*** Research into stress and coping has focused on religion as a coping strategy, referred to in the literature as religious coping (Koenig, George & Seigler, 1988; Pargament, 1997). Religion and belief have been reported as one of the most important predictors of family stress and well-being. Personal faith in a higher power or a religious philosophy of life has also been associated with effective stress reduction (Werner & Smith, 1992). Religion has been increasingly supported as relevant to physical and mental health (Cooper, 2003). Religious and spiritual involvement have been found to be inversely related to physical, mental, and substance-use disorders. (Gorsuch, 1995; Larson et al., 1986; Levin, 1994).

Frey, Greenberg and Fewell (1989) reported that belief systems and coping style are an especially important correlate of parents' psychological outcome. Weinser, Beizer and Syloze (1991) demonstrated that religious and non-religious parents differed in terms of how they perceived and talked about their experience and their child's delays. They expect that religious and non-religious families might hold different views of family life and parental roles. Religious parents might be more likely to consider their disabled child as an opportunity or challenge and less likely to consider their child a burden than would non-religious parents, they believe that their child has been given to them by God for a reason. Some parents believe that their being given a special person in their life means that God views them as special. These parents are more attached to their families than non-religious parents. They reported that religious families experienced a greater sense of peace of mind and purpose in parenting a child with disabilities than non-religious families.

Mothers who scored high in religiosity generally reported a more positive sense of well-being and less depression than mothers who scored lower (Friedrich et al., 1988). The use of religion as a buffer or coping mechanism against stress has been reported in many studies (Friedrich & Friedrich, 1981; Friedrich, Cohen & Wilturner, 1988; Friedrich, Wilterner & Cohen, 1985). Religion might have a powerful influence on parents' acceptance and adaptation to their child, and their perceived degree of stress (Beresford, 1994; Crinc, Friedrich, & Greengerg, 1983). Cohesive, harmonic families show low levels of conflict and high levels of moral-religious emphasis (Byrne & Cunningham, 1985), which is related to the coping levels of the family (Nihira et al., 1980). Also Lefcourt (1982) confirmed that belief has some control over life events and is closely linked to coping efficacy (Lefcourt, 1982).

Coping efforts are highly related to appraisal and the beliefs held by individuals (Frey, Greenberg & Fewell, 1989; Vitaliano et al., 1987). Weber and Perker (1981) and Crinc, Friedrich and Greenberg (1983) found that a strong personal faith and religious affiliation were important to the adjustment and adaptation of parents of children with intellectual disabilities. Also mothers of children with hearing and visual disabilities reported that religious beliefs had helped them care for their disabled child (Vadasy & Fewell, 1986). In addition, mothers of children with Down's syndrome who had firm religious support were more satisfied with the support that they received than less religious mothers (Fewell, 1984).

Religious beliefs and organizations are not only important to parents' coping, it is also reported that they may be particularly important as a source of support to grandparents, as they help them to accept their disabled grandchild (Hastings, 1997; Vadasy et al., 1986). However, Fewell et al., (1983) found that the effect of religion as a buffer against stress associated with parenting a child with disabilities may be more a function of parental belief than of specific support from religious organizations.

Although there are no comparative studies of all of the main religions, Catholic families always reported more acceptance of their children with disabilities than mothers from other religions (Scherman et al., 1995; Weinser, Beizer & Syloze, 1991). Focusing on religion does not preclude the importance of other cultural and social beliefs and institutions in providing an answer to suffering (Weinser, Beizer, & Syolze, 1991). Hence it is important when studying the effect of religion on families to include religion in the multidimensional model because some of the previous research has focused on a single domain, such as religious belief (e.g. Friedrich & Friedrich, 1981).

Even though many studies have focused on religion as an important predictor of family coping (e.g. Frey, Greenberg & Fewell, 1989; Turner et al., 2004), some have reported that belief has not generally been found to contribute to family adjustment (German & Maisto, 1982; Waisbern, 1982). These points of view cannot be generalized, because they are exceptional results about the importance of beliefs in families.

### 3.6.5.Social resources:

There is evidence that parenthood itself may be a challenge event (Miller & Sollie, 1980). However, the social support provided to parents is one of the most important predictors of the family outcome. Provision of support to parents is effective in buffering the stress associated with the birth of a child (Dunst, Trivette & Cross, 1986). Social support would appear to be regarded as one of the most influential determinants of the stress response (Vedhara, Addy & Wharton, 2000) since life stress and supportive interactions have been reported to predict levels of parental stress (Nakagwa, Teti & Lamb, 1992).

Crinc, Friedrich and Greenberg (1983a) noted that although the presence of a disabled child often has a detrimental effect on various family members, social support can have positive effects on the development and functioning of the target child and his/her family. Social support has powerful mediating influences on personal and family well-being (McCubbin et al., 1980; Dust, Trivette & Cross, 1986) and family adjustment (McCubbin et al., 1980). In addition Mitchell and Trickett (1980) reported that in families of children with disabilities social support mediates personal and family well-being as well as personal attitudes towards their offspring (Byrne & Cunningham, 1985; Crinc, Friedrich and Greenberg, 1983a; Crinc et al., 1983b; Dunst, Trivette, & Cross ;1986). However, Wolf et al. (1989), and Peterson (1984) assessed that it is important to determine stress moderators, and hypothesised that social support determined the relationship between stress and dysphoria.

The literature has repeatedly demonstrated a positive association between support and several indices of emotional well-being (Baker & Taylor, 1997; Hastings, 2003; Koopman et al., 1998; Vedhara & Nott, 1996; White & Hastings, 2004). More supportive social networks were associated with better personal well-being, more positive attitudes, more positive influences on parent-child play opportunities and child behaviour and development (Dunst, Trivette & Cross, 1986). In addition, many studies showed that low levels of social support are associated with high levels of symptoms of anxiety and depression (Henderson, Bryne et al., 1980; Parry, 1986a). A significant effect of support was observed in the context of pre-treatment anxiety (Vedhara, Addy, & Wharton, 2000). By contrast, Hoekstra-Weebers et al. (2001) reported that more distressed parents received more support because it aroused sympathy. Hoekstra-Weebers et al. (2001), and Wortman (1984) reported that social support seems to play a greater role in the psychological functioning and adjustment of parents and that the need for social support is higher when people experience more stress.

Mothers have been reported to be at greater of risk of future distress when they received less support (Hoekstra-Weebers, 2001). The mother's satisfaction with her social support network appears to play a more significant role in attenuating stress for mothers of disabled children (Dunst et al., 1986; Peterson, 1984). When life stress is high, mothers with a low level of support reported a higher level of parenting stress than mothers with a high level of support (Nakagwa, Teti & Lamb, 1992). Mothers report more parenting stress if support is not adequate and less parenting stress if support is adequate (Nakagwa, Teti, & Lamb, 1992). Mothers who were depressed had children with greater behavioural problems and less social support for themselves (Shariro & Tittle, 1990), whereas the extent to which mothers engaged in activities that resulted in acquiring social support, mobilizing resources, or reframing or appraising their experiences did not relate to depressive symtomology (Blacher et al., 1997).

Social support has been reported in relation to many kinds of disabilities. For example, Vaccari and Marschark (1997) revealed that parents who had greater social support in dealing with their hearing disabled children were more positive in their interaction. Calderone and Greenberg, (1993) and Luterman, (1987) also examined the level of social support from family and peers reported by mothers, and reported it to be a good predictor of the coping ability of hearing mothers of children with hearing disability. Moreover, for mothers of autistic children, the impact of parental stress on depression was suppressed by their perception of social support. Also, in parents of children with spina bifida, children's networks were more closely knit. In addition, Meager and Migrom (1996) reported that increasing social support networks might be effective in reducing the degree of depression experienced by mothers with postpartum depression. This network density was associated with high level of stress for both parents (Kazak & Marnin, 1984). Social support has been reported as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support (Dust, Trivette & Cross, 1986). They pointed out a very important point when they defined social support in terms of not only the number of sources of support available for the family, but also the degree of satisfaction with various sources of support. Barrera (1981) reported that satisfaction with support was a better indicator of emotional well-being than was network size.

***3.6.5.1. Formal Support:*** Social support has been defined by Bromely and Blacher (1989) as the presence or absence of formal and informal support. Many studies in the literature have described these two different kinds of support "formal and informal". Sandler, Warren, and Raver (1995) revealed that the power of social support to decrease the effect of stress suggests that professionals interested in promoting positive adjustment among parents of children with developmental disabilities act to encourage the maintenance of a strong social support network.

Formal support has been reported as an important resource of social support. In some studies results reported that teachers, child psychologists, doctors, and health visitors were all positively recommended as sources of advice and rated more highly than friends, grandparents and religious figures (Sonuga-Barke, Thompson & Balding, 1993). The more professionals involved, especially psychotherapists, occupational therapists, and speech therapists, the greater the parents' satisfaction appeared to be (Regan & Speller, 1989). Also, the effect of a short-term group intervention showed significant reductions in levels of guilt, negative automatic thought, internal negative attributions, and depression (Nixon & Singer, 1993). Male (1997) reported that parents were generally satisfied with the services received, but a significant proportion expressed a desire for additional services. Moreover, parents reported high satisfaction with the training programme and reported fewer symptoms of depression, parental and family problems, overall family stress and dissatisfaction with the family's adaptability (Baker, Landen & Kashima, 1991). In addition, group support programmes have been reported as an important source of formal support. Hartman et al. (1992) and Winzer (1990) revealed that social support groups promote understanding and offer parents therapeutic involvement with people with similar problems. Most families of disabled children requested daytime services as the most important one among eight types of social support (Black, Molaison & Smull, 1990). Some studies found that a teacher as a formal support was often rated more highly than medical professionals (e.g. Sonuga-Barke, Thompson & Balding, 1993).

Although many studies reported the important impact of formal support on parents' well-being and adjustment, they also reported that parents use very few formal services (Heller & Factor, 1993). Waisbren (1980) explained that sometimes public services did not play a more significant role because parents did not know about the developmental disabilities services. In addition, parents may fail to seek advice, not because they do not feel their child needs help, but because they are either unaware of the type of help available or dismiss help as unlikely to be effective (Sonuga-Barke, Thompson & Balding, 1993). The variance within the literature relating to the importance of formal support has been explained by Mirfin-Veitch, Bray and Watson (1997) who pointed out that it is important that methods of assessment of families' needs for formal support services are designed to take into account their access to acceptable informal support from extended family members. That means families who have strong sources of informal support might need less formal support, but those who have weak or no informal support need more formal support.

***3.6.5.2. Informal support:*** Most of the studies which studied stress and adjustment in families of disabled children, focused on the importance of informal social support (spouse support, friend support, and relative support) to reduce stress in parents of children with disabilities (Heller & Factor, 1993). Family and friends have been reported to be the most informally supportive for parents. Kwai-Sang Yau and Tsang (1999) reported that the family system's positive reorganisation following the birth of a developmentally disabled child leads to a higher level of parental utilization of extended family, friends and professional resources.

Families must be considered as genuine partners, rather than simply a group of people (Knox et al., 2000). The family has been seen as more supportive compared to friends. Dunst, Trivette and Cross (1986) indicated that intrafamily support has greater influence on maternal behaviour and attitudes than either friendship or community support. Moreover, Abercrombie, Hill & Turner (2000) reported that only 7 per cent of people say that their friends are more important than their families. It has been reported that the presence of a family member with a disability may contribute to the strengthening of the entire family unit, as well as contributing positively to the quality of life of individual members of the family (Summer et al., 1989; Wikler et al., 1983; Winzer, 1990; Kwai-Sang Yau & Tsang, 1999).

The extended family is the most effective resource for most parents of disabled children. Before I review the effects of the extended family, it is important to define it. Sonnek (1986) revealed that the term has many different interpretations. It may be defined broadly to include all persons, regardless of sex or bloodline, who are related to a nuclear family; it may include only those persons of a particular bloodline or sex (e.g. maternal grandparents or aunts, uncles), or it may refer to both a particular bloodline and sex (e.g. paternal grandfathers). Marshall (1998) defined the extended family as a family system in which several generations live in one household. On the other hand, Sutherland (1995) defined it as a family that includes members other than just the parents and children (e.g. grandparents, cousins).

"Modified extended family" is a new concept of extended family reported in the literature. Sonnek (1986) reported that the definition of a modified extended family is not always clear. Does it describe the grandparents' relationship, or does it include the relationship with siblings, aunts, and uncles of the nuclear family? Because discussion of the extended family usually tends to focus on the role of grandparents with few references to roles of other extended family members, the modified extended family is distinguished by a network of mutual aid and support between generations in spite of geographic distance separating them (Sonnek, 1986). Abercrombile, Hill and Turner (2000) indicated that the typical family form in modern industrial societies is not, therefore, the isolated nuclear family but a modified extended family. Recent studies (Abercrombile, Hill & Turner, 2000) have established that most people in modern Britain live within one hour's journey of parents, siblings, and other relatives and they see them at least monthly. When they live more remotely, contact is maintained by telephone or other means. In addition, Sonnek, (1986) characterised family life in the United States as a "modified extended family system" rather than as an isolated nuclear unit.

The extended family as well as the child's family may be affected by the disabled child (Gabel & Cotsch, 1981; Schell, 1981). But, when extended family support exists, it tends to reduce stress and enhance personal family functioning, as well as influencing the well- being of children in the family (Byrne, Cunningham & Sloper, 1988). Spousal support was reported as an important resource used to cope with the challenges of rearing a disabled child (Kwai-Sang Yau & Tsang, 1999). Also, Abbott and Meredith (1986) revealed that the support of the spouse is the most helpful resource for these parents.

***3.6.5.2.1. Grand parents support:*** Grandparents and extended family members are one of the most important sources of social support for parents of disabled children (Gabel, Scwartz & Kotsch, 1981). In general, children with extended families have fewer behavioural problems and less serious problems, moreover, grandparents in extended families may increase children's resilience by providing sources of attachment and knowledge when they support the parents (Hwag & James, 1999). In addition, Hastings (1997) reported that grandparents and older extended family members are viewed as a valuable asset to a child who is developmentally disabled as well as to his/her parents and siblings. A significant positive correlation between paternal adjustment and grandparent support (e.g. Marsh, 1992; Sandler, Warren & Raver, 1995; Seligman, 1991) and how grandparents fulfil valued and vital support roles, was found in many studies (Beresford, 1994; Sonnek, 1986; Vadasy & Fewell, 1996). When a family is faced with a crisis, the role of extended family members may take on additional significance (Sonnek, 1986). The main goal of the extended family component is always to enhance support for the children and their parents (Gabel, Scwatz, & Kotsch, 1981) and the typical grandparents' role is to provide support to the nuclear family

(Sonneck, 1986). The needs of extended family members will ideally be addressed as part of the overall treatment approach with children who have chronic illness and/or developmental disabilities (George, 1988).

Grandparents and other extended family members also play critical roles in the development and validation of the parents' identity (Gabel, Scwatz & Kotsch, 1981). Moreover, they influence the development of disabled children in direct interaction with them and through the nature of support provided to their parents (Gabel, Scwatz & Kotsch, 1981). Extended family contact is an integral component of the general functioning of the family (Mirfin-Veitch, Bray & Watson, 1997). Extended family members maintain important functional links with one another; and they exchange emotional support and material aid (Gabel, Scwatz & Kotsch, 1981).

When a child is diagnosed as having a disability, the relationship history between family members, as well as the sort of family to which they belong affects how grandparents react (Mirfin-Veitch, Bray, & Watson, 1997). The grandparents are often the first people contacted after the parents learn of the child's disability (Vadasy, Fewell & Meyer, 1986). In a small number of couples, grandparents accepted the fact of a child's disability even before the parents did (Mirfin-Veitch, Bray & Watson, 1997). Some of the grandparents were concerned about the amount of stress that having a child with a disability placed on their children's marital relationship (Scherman et al., 1995). If grandparents react positively to the diagnosis of a disability, their behaviour serves as a model for the rest of the family (Mirfin-Veitch, Bray & Watson, 1997). Grandparents are often reported as one of the most important sources of support for families of children with disabilities (Hastings, 1997). In extended families grandparents would occasionally remind family members of how their family would respond to the fact of a child's disability (Mirfin-Veitch, Bray & Watson, 1997). Hastings (1997) reported that support from grandparents may reduce the stress parents experience. Mirfin-Veitch, Bray and Watson, (1997) reported that if parents and grandparents form an extended family share a positive relationship history, they will commonly share a supportive relationship.

Many earlier studies showed that grandparents often function as an important source of emotional support (e.g. Click, 1986; Schell, 1981; Vadasy, Fewell & Meyer, 1986).

Moreover, there is a significant positive relationship between parental ratings of grandparents' support and parental adjustment (Sandler, Warren, & Raver, 1995). They are an active and significant part of the family system, which includes a grandchild with special needs (Scherman, 1995). Most grandparents show understanding about problems related to their disabled grandchild, and they are always available to discuss such problems (Hornby & Ashworth, 1994).

Grandparents were identified as providing two distinct types of assistance, which can be classified as follows: 1) practical (or instrumental) support (e.g. babysitting, household chores, care, financial support), and 2) emotional support (e.g. listening ear, non-judgemental advice, acceptance of the child's disability, affirmation of parents' coping ability) (Hastings, 1997; Mirfin-Veitch, Bray & Watson, 1996). Hastings (1997) revealed that there is less information available about emotional support. Practical support (instrumental support) provided by grandparents has been reported in the literature, including baby-sitting, help with shopping, and financial support (Vadasy et al., 1986). Hornby and Ashworth (1994) reported that grandparents provided help with shopping, help with household tasks, having grandchildren to stay overnight with them, and occasional or regular financial support.

Fitzegrald, Butler and Kinsella (1990) reported that parents in nuclear families found it difficult to get a babysitter. Relatives were not typically anxious to get involved or help and neighbours tend to ignore them. However, this is not felt to be true of families who have relations living nearby and where the child is accepted as having a problem and the extended family is available to baby-sit and give parents a period away from parenting. Therefore, baby-sitting is one of the most instrumental supports provided by grandparents (especially grandmothers) (Gerver, 1983; Sandler, Warren & Raver, 1995; Sonnek, 1986; Sandler, 1998; Sandler, Warren & Raver, 1995;Schilmoeller & Baranowski, 1998). In addition, indirect finance in the form of gifts of clothing or toys of their grandchild (Gerver, 1983; Sonneck, 1986; Vadasy et al., 1986; Schilmoeller & Baranowski, 1998), transporting children to school, taking children to medical appointments (Schilmoeller & Baranowski, 1998), and help with the child's educational expenses (Sonnek, 1986) were reported. In addition, grandparents always reported giving traditional support such as baby-sitting and attending school ceremonies (Garndner et al., 1994; Scherman et al., 1995).

Although Hewett, Newson and Newson (1970), (cited in Sherman, 1995) reported that grandmothers of disabled children served as sources of strength even when there was considerable distance between the mother and grandmother, it is worth mentioning that grandparents who lived closer to their children were generally more involved in the daily running of their children's household and spent more time with their children and grandchildren than did those who live farther away from their children (Scherman et al., 1995). In addition, Seligman et al. (1997) mentioned that grandparents who are close by can offer emotional support and are in a particularly good position to offer particular help to their children and grandchildren.

***3.6.5.2.2. Grand parents' negative role:*** While some grandparents accept the situation, others deny the problem or its severity and insist that the child will grow out of it (DeLuca & Salerno, 1984). Sandler (1998) reported that although the support of grandparents can be an invaluable resource for family members, grandparents are sometimes a source of stress. Scherman et al. (1995) noted that sometimes grandparents' reaction to the birth of a disabled child include denial, grief, anger, guilt, blame and depression. It is common for grandparents not to understand the child's problem and believe that nothing is wrong with the child (Vadasy et al., 1986). Grandparents who deny the child's disability in an attempt to avoid the pain, often become a burden for the parents (Gabel & Kotch, 1981;

Seligman, 1991). Moreover they sometimes report feeling deep concern about their grandchild's future (Vadasy, Fewell & Meyer, 1986). They sometimes contribute to the stress experienced by family members. In the words of one parent "they can make it a whole lot easier, or a whole lot harder" (Simon, 1987, p.30).

For a smaller number of families, Mirfin-Veitch, Bray and Watson (1996) found that grandparents were not considered to be a source of support. Moreover, Mirfin-Veitch, Bray and Watson (1997) pointed out that when grandparents do not provide practical and/or emotional support to parents, the parent-grandparent relationship was classified as less involved. Hence, formal support services need to be readily available to the families who fall into this category (Mirfin-Veitch, Bray & Watson, 1996). Similarly, Mirfin-Veitch, Bray, and Watson (1997) noted that if parents and grandparents display a history of problematic relations and little support, intervention of another kind may need to be implemented. Consequently, grandparents may constitute an additional burden on families of children with disabilities (e.g. Gabel & Kotsch, 1991; Seligman, 1991). In Hornby and Ashworth's (1994) study, 24% of grandparents were reported to have added to the family's burden. Also, the results of that study revealed that only a quarter of grandparents were considered to have added to the parent's problem and almost a third of the parents expressed a wish for more support from grandparents. George (1988) pointed out that almost 80% of families of children with epilepsy noted that a grandparents' support was the least helpful in their adjustment.

In some cases grandparents may impede the adjustment process of parents (Sandler, Warren & Raver, 1995). Such reactions from the grandparents may even lead the parents to isolate themselves from their extended family (George, 1988). All of the previous results focused on the importance of grandparents' support and how families who received less support may experience more stress. Waisbern (1980) reported a very different finding; that more symptoms were reported by mothers and fathers of children with highly supportive grandparents.

***3.6.5.2.3. Differences between paternal and maternal grandparents support***: Differences between paternal and maternal grandparents and differences between grandmothers and grandfathers should be taken into account when justifying these opposite findings about grandparent support. Seligman et al. (1997) showed that grandmothers were perceived to be more supportive than grandfathers, the father's mother was less supportive that the mother's mother, and mother's parents in general were judged to be more supportive than the father's parents. However, Kahana and Kahana (1971) (cited in Sonnek, 1986) said that maternal grandmothers and paternal grandfathers appear to be most supportive of the child-rearing techniques practised in the family. Harris, Handleman and Palmer (1985) also found that significantly more support was provided by the mother's family than by the father's family. Hornby and Ashworth (1994), and Bryne et al. (1988) also reported that more support was received from maternal grandparents than paternal grandparents. In addition Gath (1978)(cited in Sandler, 1998) pointed out that maternal grandmothers have provided much support during the child's first year. They (maternal grandmothers) have also been identified as an important source of support for mothers (Levitt et al., 1986). They are likely to provide more assistance in exceptional families (Goetting, 1990). This might be because closer ties exist along maternal bloodlines than along paternal bloodlines. Women's identification with their mothers is one of the most important influences on woman's maternal roles (Sonnek, 1986). They visited more frequently than paternal grandparents (Hornby & Ashworth, 1994). Maternal grandparents not only help their daughter cope with a newly born infant but also compensate for the lack of support and even perhaps the negative emotion being expressed by the husband's family (Seligman et al., 1997).

Because maternal grandmothers were perceived as providing help to their daughter, paternal grandmothers were perceived as being unsympathetic to their daughters-in-law and were frequently thought to blame the daughter-in-law for the child's disabled condition or for placing an excessive burden on their sons (Sonnek, 1986). Moreover, Piper (1976) (cited in Seligman et al., 1997) reported that the father's parent may blame the mother for the child's disability and hold her accountable for their son's chronic burden. These feelings from in-laws can be expressed in angry and unsupportive ways towards the daughter-in-law thereby creating stress for the mother, which can result in destructive family interaction. Simons (1987)(cited in Sandler, 1998) reported that parents-in-law disapproved when the mother of the child with Down's syndrome failed to follow their advice to feed the child vitamins and get future testing done; they told the mother that she wasn't being a good mother. Mothers-in-law may blame the mother for the child's disability (Sandler, 1998). Therefore, her own mother tends to promote higher marital integration, whereas frequent contact with her mother-in-law can have negative influence (Seligman et al., 1997). Many studies have concluded that in-laws are usually not a valuable source of support during times of personal crisis (Geoting, 1990), in contrast mothers describe that having parents-in-law, or other relatives living in the same house or nearby is helpful (Sonnek, 1986). Mothers who perceived their in-laws to be supportive had more positive relationships with their disabled children and made fewer visits to the doctor than those perceiving their in-laws as non-supportive (George, 1988; Seligman et al., 1997; Waisbern, 1980).

Finally, It is worth mentioning that social support is a multidimensional construct that includes physical and instrumental assistance, attitude transmittion, resource and information sharing, and emotional psychological support (Dunst, Trivette, & Cross, 1986) from an extended family. It is more important to measure social support in terms of both satisfaction with various sources of support and a number of sources of support available to the family (Dunst, Trivette & Cross, 1986). Satisfaction with support was a better indicator of emotional well-being than network size (Berra, 1981). Therefore, it may not be relevant who provides more support, (paternal or maternal grandparents), it is more important whether this support satisfies both parents or not.

In conclusion, the previous discussion focused on the importance of grandparental support to parents of disabled children. Most of these studies tried to find relationship of the effects of child disability on grandparents and how it affects grandparents' support to their sons/daughters who have children with disabilities.

## 3.7.Multicultural issues in stress and coping:

A family's cultural values are possibly the most unchanging element of the family and can play an important role in shaping its ideological style, interactional patterns, and functional priorities (Turnbull et al., 1986). Cultural differences and ethnicity play a significant role in determining parental stress (Wishner, 2002). Hobfoll (1998) pointed out that there are cultural differences in coping patterns. He suggested that western individualistic values and the non-western collectivist views can influence an individual's coping style in different ways. The ideological style of families that is based on their beliefs, values, and coping behaviours are also strongly influenced by their cultural style (i.e. ethnicity, race, religion, and geographic location of the family) (Ezinwanyi, 1999).

However, there is minimal information available concerning the impact of ethnicity and cultural differences upon maternal stress. There is little research detailing cultural differences among families of disabled children and their experiences with stress and coping. Most of the research focused mainly on Caucasian participants (e.g. Warfield, 2001; Dyson, 1991; Heller et al., 1997; Rodrigue et al., 1992). Moreover, some studies (e.g. Frey et al., 1989; Gray, 1997; Krauss, 1993) failed in their studies to indicate the cultural breakdown of the participants. Even some studies (e.g. Marcenko & Meyers, 1991) which included participants from different ethnicities (Caucasian, African-American and Hispanic), failed to analyse cultural influences upon mothers' perceptions of support.

According to Kwan (2002) there is a cultural impact on the management and expression of emotions. There are also cultural variations in the appropriateness of certain expressions of emotion such as laughing and crying. This cultural impact on emotional expression would also impact on the individual's cognitive appraisal of the stress situation. Lazarus and Folkman (1984) noted the importance of culture in impacting on individual's emotions in which "the same events may be fear-inducing in one culture, anger-inducing in a second, and benign in a third" (p.228). Hobfol (1998) argued that perceptions are tied to one's cultural heritage. He believed that perceptions are influenced by underlying factors, including individual's interpretation of factors based on cultural biases, interpretations based on family norms and rules, and illusions based on individual, family, and cultural biases.

In another example of cultural differences, in ethnic groups living in the UK, Ellahi and Hatfield (1992) found that respite care was accepted by only one third of Asian families surveyed. Reasons for non-use include parents choosing not to use it for religious or cultural reasons, such as the fear that their child may be given meat which was not Halal, or concern that allowing daughters beyond the age of puberty to stay away from home may result in their mixing with the opposite sex. It is not clear what specific ethnic factors accounted for these differences (Betancourt & Lopez, 1993).

To sum up, because there is no universal parental reaction to a child's disability (Kwai-Sang Yau & Tsang, 1999), the culture, ethnicity or race of the family does matter in some cases and in the light of the limited research into the cultural impact of having a disabled child and into family stress and coping, additional studies need to address multicultural issues within such minority groups. Stressing the need for a multicultural approach, the next chapter will discuss some of the few studies which have looked at non-western families and specially the very few published studies about middle Eastern, Arabic and Muslim families with disabled children.

## 3.8.Conclusion:

This chapter reviewed the literature on the attributes of the psychological impact on parents of children with developmental disability in western societies.

Raising a disabled child has been reported to be more challenging than raising a TD child (Cahil, 1996). The former places major emotional and behavioural indicators on the family, such as shock, disbelief, denial, confusion, sadness, self-blame, helplessness, insecurity, social withdrawal, and a feeling of being intimidated. These impacts can sometimes cause two major psychological problems: stress and mental health problems or emotional disorder (anxiety and/or depression). Mothers have been reported to be more affected by their child's disabilities than fathers.

Although most of the literature has focused on the negative impact of the disabled children on their families and especially on their mothers, other studies have reported that these families are not a homogeneous group and that they are likely to show variation in their responses. Some families adapt and cope successfully. Moreover, many families have a positive perception of raising a disabled child. Although these families might report negative outcomes, positive outcomes were also sometimes manifested in this group.

Though there are no conclusive findings, consistent patterns emerge in relation to a few factors that enhance family coping and facilitate parental adjustment to the birth of a disabled child. These include the kind of coping strategies that have been used by the parents. Parents can use the coping strategies that they find work best for them. Problem-focused coping is associated with a lower level of stress than emotion-focused coping.

Some personal resources in parents might reduce stress and mental health problems. Better education, maturity, a smaller number of children, a strong spousal relationship, and a strong parent-child relationship have all been associated with less stress and emotional problems for parents, whereas inconclusive results have been reported with regard to maternal employment.

Characteristics of the disabled child might also have an impact on the outcome for his/her parents. A younger female child with a less severe disability, fewer behavioural disorders, and certain types of disability (e.g. Down's syndrome) might have less negative impact on his/her parents than others.

The family's characteristics are considered to be an important influence on parents' outcomes. Married couples with few children, a high socio-economic status, more religious, living in a supportive community, and where there is less stigma in their community are more likely to experience better outcomes than other parents.

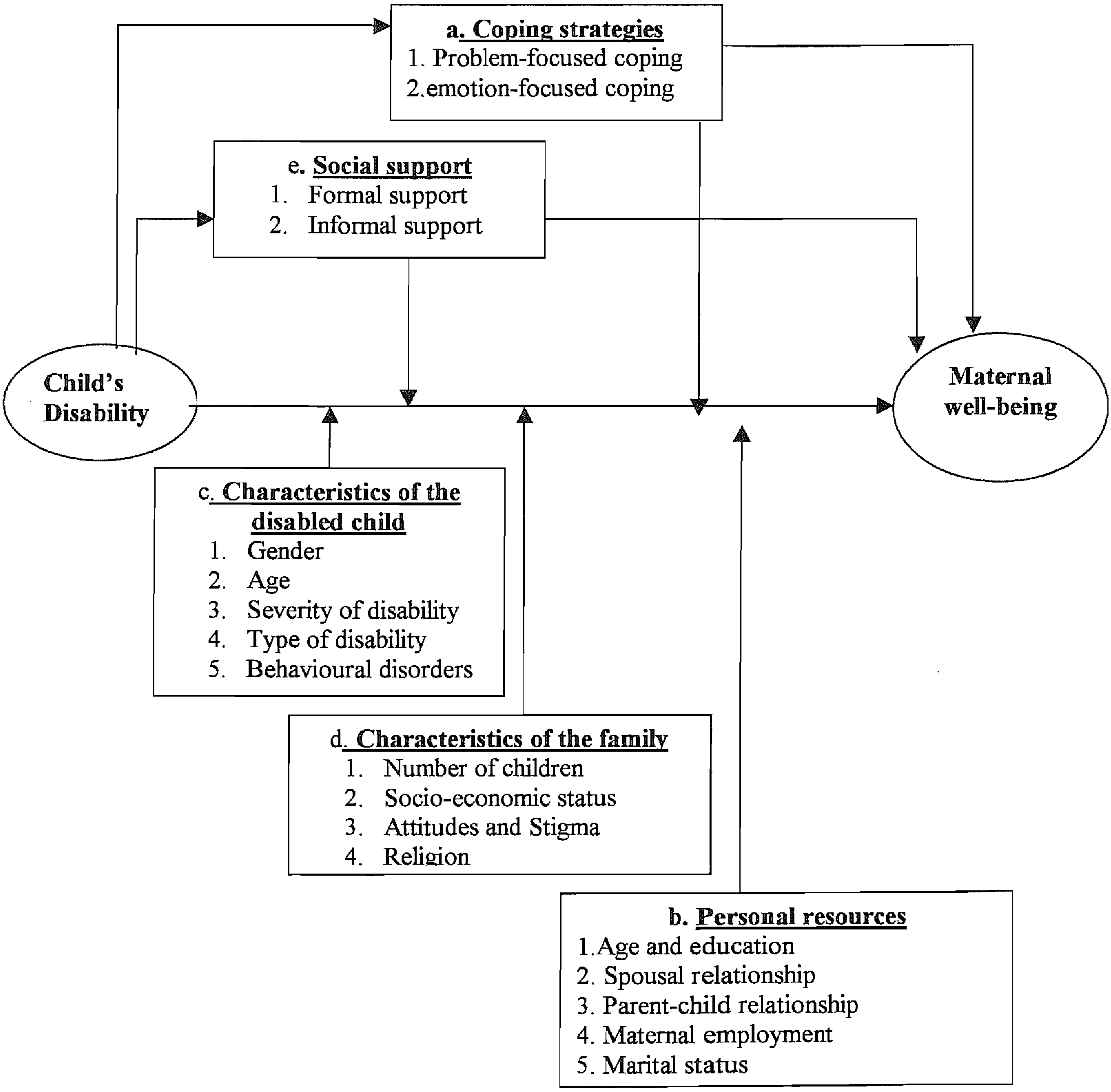
A number of sources of support and satisfaction within various sources of support to parents, either formal (medical staff, teachers, or integration groups) or informal support (specially from extended family and friends) are also important in determining parents' outcome.

Nevertheless, as parents or families with disabled children are not a homogeneous group, and because there is no global stress and coping theory, most of the pioneering theories apply to western culture. Professionals need to observe and respect the uniqueness and individuality of each parent and family (Kwai-sang Yau & Tsang, 1999). This chapter has not dealt with adaptation in other forms of family in other ethnic groups, cultures, and other geographic locations (rather than the USA and the UK). Professionals also need to be careful when they apply the above findings in practice and should avoid generating stereotypes, particularly when working with families from different cultural backgrounds. This makes it essential to conduct another study of a different cultural view, among families from non-western societies, to compare and contrast these two types of family and to consider whether or not we can apply western theories to other cultures.

The following path model (Figure 9) indicates most of the findings in literature, which have been addressed in this chapter. It summarized most of the previous findings of the relationship between disability and maternal well-being. Most of the studies focused on maternal stress, and sometimes anxiety or depression, as an outcome which will be presented in the model as maternal well-being, where coping and social support have sometimes been addressed as mediators and sometimes as moderators. Both mediating and moderating paths were included in the model.

Characteristics of child and family and personal resources have always been used as moderators and sometimes they have a direct effect on maternal outcomes. All potential characteristics of child and family were presented in the model as moderators. The next chapter will present probabilities of modifying this model based on the literature of the non-western studies of families with disabled children.

Figure 9: Model of the previous literature relating stress, coping and mental health



# CHAPTER 4

# FAMILIES OF CHILDREN WITH DISABILITIES (NON-WESTERN VIEW)

## 4.1.Introduction:

Until recently, cultural issues in the perception and measurement of psychological states received little attention due to the influence of the universalist approach (Marsella & Kameoka, 1989). The main purpose of this chapter is to briefly summarise the main findings of Arabic studies undertaken in non-western countries (the Middle East, in particular). Including the socio-cultural context of Saudi Arabia in the perception and development of children and their families.

It is of great theoretical interest to have an idea of the similarities and differences in the conceptualising of human behaviour in the light of different cultures (Al-Awad, 1997). Some empirical evidence exists to suggest that psychological disorders may vary in rate, diagnostic pattern, and expression across different cultures (Reid, 1995). This chapter tries to highlight the situated nature of western family psychology and question its relevance and applicability to non-western developing countries.

Developing countries have to be recognised as having their own cultural orientation as a basis for psychological practices (e.g. Triandis & Brislin, 1984; Wagner, 1986; Marsella & Kameoka, 1989; Al-Awad, 1997). In non-western societies there is a range of life styles and approaches to child-care that differ from those prevalent in the west (Al-Awad, 1997). Themes such as cultural variability and cultural sensivity related to children and the assessment of behaviour problems must be thoroughly addressed (Bird, 1996). It is also important to realise the role of religion as the most significant difference between western and non-western child-care and development (Al-Awad, 1997).

It is important to note that childhood in any culture has specific characteristics in addition to the biological and human characteristics that are universally shared with other children (Al-Awad, 1997). Although there are many differences between Arab (non-western) and western families, this does not mean that they are completely different, as they share the same social system (Al-Samadi & Al-Husain, 1996). The Arab family has some features in common with any other familial system as well as having characteristics that distinguish it from western families (Al-Samadi & Al-Husain, 1996). Therefore, the universal applicability of diagnostic resources for solving child and family problems should be questioned (Abolfotouh, 1997). Al-Kheraigi (1989) reported that the disabled individual may have more or less similar problems to those of their counterparts in western societies. However, the Muslim, Arab disabled may have other problems that are not found among the disabled in other societies, because of the unique construction of their society. For example, because the disabled are well protected by their family, qualities of independence and self-reliance may not be part of child rearing in Saudi Arabia. For example, the researcher who works in Arab societies (specially the Saudi society), should know that any unknown enquirer who visits someone's home is normally turned away: "Good" people do not arrive uninvited. It may be more acceptable to meet people at "a recognised place" than at home. Moreover, researchers should use culturally-appropriate ways of relating and talking to people, including talking to the family through the father (Akhdar, 1994). Akhdar (1994) cited Saudi Arabia as an example of a Middle-Eastern country where the problems of mental abnormality are coming to the forefront, although most cases of intellectual disability remain without adequate explanation.

There are few studies that deal with the Arabic family system, and there are also very few psychological and sociological studies about Arabic families (e.g. Akhdar, 1994; Al-Samadi & Al-Husain, 1996; Al-Awad, 1997). The Arabic family faces different challenges than those faced by western families because of the changes and new lifestyles which have come about in most of Arabic societies (Al-Samadi & Al-Husain, 1996). This chapter including Eastern studies about families of children with disabilities. Eastern cultures are said to be collectivist with strong family values and members have their expectations of families through achievement, obedience, and conformity to social rules. (Shin, 2002). When a member of a family faces problems, they tend to depend upon the family for problem-solving instead of looking for outside sources of help. Western culture is, on the other hand, more individualistic, focusing on meeting the needs of individuals through achieving personal rather than family goals and bringing honour to the individual rather than to the family (Shin, 2002).

In order to report these differences, the following steps will be discussed in this chapter. Factors that differentiate families in non-western societies (especially, Arabic and Islamic), such as the size of the family, family structure, marriage systems, and importance of religion will be discussed. In addition, we will go into disability in non-western societies focusing on the initial reaction to disability and variability in stress. Finally we mention the importance and nature of social support in non-western cultures.

## 4.2 Factors that distinguish Arabic, Islamic families:

### 4.2.1. Size of the family:

It is known that fertility and family size in developing countries are larger than those in developed countries (Al-Said, 1988) and Arabic families differ from western families in their desire to have more children (the mean family size in the Arab world is 5.8), whereas the western family mean is 2.8 and this is a significant difference between these two cultures (Al-Samadi & Al-Husain, 1996).

High marital fertility is usually associated with religious societies. Spillane and Rayser (1975, cited in Al-Said, 1988) found in their study that religion was a very important factor. Even in western societies, Catholic men desire more children, have achieved greater parity, and are expected to have larger families than Protestant men. Coward and Wilson (1985) also examined the relationship between family size and religious denomination in Northern Ireland. They found that Roman Catholic families were bigger than non-catholic families. With regard to non-western societies, Al-Said (1988) also pointed to the high fertility of Buddhists and Hindus, which was exceeded only by that of Muslim communities. Islam, like other religions has a strong and effective influence on fertility. Muslims are encouraged to have high fertility rates and large families (Al-Said, 1988). Gadalla (1978) (cited in Al-Said, 1988) mentioned that Islam is a religion that gives strong and unequivocal emphasis to high fertility. Therefore, Islamic countries uniformly have high birth rates (Al-Said, 1988). Total fertility rates for each of the 30 Muslim countries was noticeably higher than those for non-Muslim countries in the same region, and substantially higher than the world average (Nagi, 1980). Ahmed (1985), in his study of marital fertility in the four Muslim populations of Bangladesh, Java, Jordan and Pakistan, found that desire for more children was found in all of these Islamic countries. Fertility, when controlled for duration of marriage, was found to be higher in urban than in rural areas. Chami (1981), in his study of religion and fertility in Lebanon, mentioned that the respondents considered four children to be the ideal family size. In Egypt, the majority of women with two or more children stated a desire for more children (Al-Said, 1988). Sebai (1979) (cited in Al-Said, 1988) reported that six children was the desired number among villagers in the western part of Saudi Arabia, and that males were preferred. Al-Said (1988) reported that most Saudi families desire a large family. The average family size is 7.7, which indicates the total number of children that were born to women between the ages of 15 to 49. He (Al-Said, 1988) found that no significant effect of duration in the United States was found on fertility and family size. Most respondents of Saudi origin living in the USA perceive five children as the ideal number. They agreed that the present size of the Saudi population is not large enough. Moreover, respondents who were more religious were more likely to prefer a large family.

The idea of having a large number of children is still in existence in the Islamic and Arabic world. Fouzan (1986) revealed that parents in the developing countries should be encouraged to consider the issue of family planning. Although some studies (e.g. Al-Awad, 1997) showed that large family size did not have any repercussions on behavioural problems. Instead, Al-Awad (1997) revealed that it was associated with reduced symptoms of fidgeting, unsociability, and sleep problems, whilst many studies have reported the opposite. Parents with lots of children devote less time to their children individually (Al-Garni, 2000). Angenent and De Man (1996) revealed that in large families, children get fewer marital benefits than their counterparts in similar families. Large families of four or more children were more likely to have a child with a behavioural disorder as compared to a small family (Abolfoutouh, 1997). Large families have more delinquency than smaller families (Al-Garni, 2000). In addition, a large family is the most significant factor in the increased likelihood of deviant behaviour among adolescents (Al-Garni, 2000).

The tendency towards large families in Arabic (specially Saudi) societies has its roots in the religion of Islam. There are three explanations for this tendency: 1) Islamic conventions urge people to have many children. The father views children as a display of his manlihood and self identity, 2) polygamy (i.e. marrying more than one wife but four or fewer) is permissible for Muslims, and 3) Large families are viewed as a source of power and physical support in tribes, which pervade the Saudi community, since it consists of a collection of tribes (Al-Garni, 2000). Husbands in general want more children because they are symbols of wealth, strength and vitality. Moreover, they believe that it enhances the reputation of their family and protects their kinship (Al-Said, 1988).

A few studies have reported some changes in family size in Arabic and other Islamic countries. Al-Ghamdi (1991) revealed that prolificacy had declined in families and a smaller family was becoming preferable among the young Saudi generation, particularly in urban areas, because in the past the financial costs never showed up as a real economic problem, nowadays it does. In addition, polygamy, which was formerly common in days gone by, has tended to decline significantly. Few males were found to be still practising polygamy (Al-Ghamdi, 1991). Al-Obeidy (1985) argued that high prolificacy is associated with low socio-economic status. Thus families with high socio-economic status are likely to have fewer children than those with low socio-economic status.

These non-western cultures might have a different family structure than western cultures that encourage them to have big families. Extended and nuclear families are two different types of family, which might vary in breadth between cultures.

### 4.2.2. Family structure:

Notions of "tribe" which are based on genealogy, continue to organise structure in Arabian populations. Fandy (1999) observed that the idea of familism, which is based on relationships involving interdependence, protection, and accountability, predominated, with Arabs and Saudis regarding themselves as part of an extended family.

Islamic and Arabic developing countries traditionally adopt the extended family form (e.g. Al-Awad & Sonuga-Barke, 1992; Al-Samadi & Al-Husain, 1996; Al-Said, 1988). Abdelrahman and Morgan (1987) showed that approximately 50% of families living in Khartoum adopted the extended family structure, 30% live with the mother's family and 20% live with the father's family. In Sudan, the extended family is embedded within the wider communal structure of the tribe (Al-Awad & Sonuga-Barke, 1992). Families traditionally consist of three or more generations, with siblings living side by side and sharing domestic duties and economic responsibilities. The extended family is the basis of Saudi society, and it is composed of a couple, married sons, parents, and children. The household typically includes three generations (Al-Said, 1988). Alhammadi (2000) and Al-Turaiki (1998) also revealed that most Saudi families are large. Evidence from industrialised societies shows that extended family ties can persist, where Islamic culture and spiritual beliefs reinforce such order and strong kinship relationship (Al-Ghamdi, 1991).

Arabic people often prefer to live within the extended family. However, a trend towards a preference for a nuclear family structure is observed throughout the Middle East in the latter part of the 20th century (Rugh, 1985). Some researchers pointed out that the nuclear form of family is starting to take its place in Arabic societies because of rural to urban migration (Al-Samadi & Al-Husain, 1996). Al-Awad and Sonuga-Barke (1992) revealed that although the extended family structure still dominates social life in rural areas, in the city a large proportion of families are now based on the nuclear unit common in the western societies. Families of the new generation, who live in a time of socio-economic changes, tend to be small in size and nuclear (Al-Ghamdi, 1991). Al-Said (1988) noted that many mothers reported geographical segregation from their parents or relatives. Hence, the extended family is declining and the nuclear family household is increasing rapidly (Al-Ghamdi, 1991).

In a study of extended and nuclear families in Sudan (Al-Awad & Sonuga-Barke, 1992) families of children between the ages of 4 and 9 were compared on the basis of the mothers' rating of a range of childhood problems. Interviews were carried out with mothers and the discussions were loosely structured around the eight categories of childhood psychiatric problems suggested by Ross (1980). Results showed that the grandmother in the extended family take over the mother's chores while the child is being nursed, leaving the mother to develop an extremely close and intimate relationship with her child. Mothers in nuclear families are less likely to breast feed and tend to wean much earlier than those in extended families. Children living in nuclear families were associated with more behaviour, emotional, and sleep problems, over-dependence, and poor overall self-care, than those in extended families. Moreover the latter were more likely to be breast-fed, to be weaned later, and to have grandmothers involved in childcare. Even in some ethnic groups living in western society, Wilson (1986) revealed that black American children who live in extended families did better at school and exhibited better adjustment and were more sociable.

Whilst most of the studies in the area reveal the advantages of living in an extended family, others reported the opposite. Sonuga-Barke, Mistry and Qureshi (1998) reported that the rate of anxiety and depression among the British Pakistani Muslim mothers living in an extended family were high. Grandmothers had more traditional attitudes to child-rearing than did mothers, and integrational discrepancy over child-rearing was more marked in more acculturated families, and this discrepancy was associated with higher levels of anxiety and depression. Shah and Sonuga-Barke (1995) reported similar findings. They examined the relationship between family structure and mothers' mental health in a British Pakistani Muslim community. Thirty-five mothers with 6-11- year-old children were recruited. The average age of the mothers was 33.4. Three scales were filled out by mothers, the hospital anxiety and depression scale, a shortened nine-item version of the acculturation index, and demographic information. Teachers completed the Rutter teachers' scale to measure child behaviour adjustment. Results revealed that mothers who live in extended families reported feeling more depressed and anxious than those in nuclear families. However, their children were better adjusted. The explanation of these results might be not because they live in extended families but because they were from an ethnic minority (Pakistani) who lives in a completely different culture (U.K), because of this the differences between the older generation (grandmothers) and the younger (mothers) will be exaggerated and make mothers more anxious and depressed.

### 4.2.3. Gender role:

In Arabic societies, connectedness is experienced within the context of gender and age, with male and older family members entitled to oversee the lives of females and younger members (Viogtman, 2002). Households are held together by strong, affiliative female members, and controlling, directive fathers who strengthen the family relationship with the community (Voigtman, 2002)

Gender has a considerable effect on child-rearing and the development of affective bonds. While a Middle Eastern Arab father provides much of their child's identity, including citizenship, religion, and family alliances, the mother-child relationship is characterised by mutual unconditional love and idealisation of the mother figure (Joseph, 1999).

Socialisation into gender roles in Middle Eastern, Arab families is also accomplished with the siblings as brothers assume protective and supervisory roles for sisters and younger siblings (Voigtman, 2002).

### 4.2.4. The marriage system:

The marriage system in Arab societies is different to some extent from that in western societies. Arranged marriages and internal family marriages are still practised in most Arab countries, especially among the rural population (Al-Ghamdi, 1991; Al-Awad, 1997). Narchi & Kulaylat (1996) reported that the incidence of intermarriage (marriage between relatives, especially cousins) in Saudi families is 70%, 40% of which are first-degree. In addition, Schneider (2000) revealed that 58% of marriages between relatives are between first and second cousins or more distant relatives. Narchi and Kulaylat (1996) showed that, especially in the eastern part of Saudi Arabia, consanguineous marriages are very common. Abdelrahman & Morgan (1987) and Al-Awad and Sonuga-Barke (1992) revealed that in Sudan, marriages occur early and are arranged by parents and are frequently between cousins or other family members. Al-Ghamdi (1991) also reported that marriage within the extended family is very common in Saudi Arabia. One reason for marrying a cousin is to maintain the wealth of the family within the extended family.

Although the arranged marriage and the marriage within the family are still practised among the rural population (Al-Ghamdi, 1991), the internal marriage has sometimes appeared to cause many problems for the family. Congenital malformations are more prevalent in populations with a high intermarriage rate, including in Saudi Arabia (Narchi& Kulaylat, 1996). Blood disorders such as Thalessemia, sickle-cell anaemia and diabetes are widespread particularly in provinces with high intermarriage rates (Schneider, 2000). The rates of some metabolic diseases may be as much as 20 times higher among Saudi Arabian people than they are where the gene pool is more widely mixed (Schneider, 2000). Some kinds of intellectual disabilities (ID) such as fragile X syndrome are reported to be high in families with internal marriage (Ikbal, Sakati, Nester & Ozand, 2000; Al-Husain et al., 2002). Some diseases are more likely to appear in certain tribes (Schneider, 2000). Therefore, media and religious authorities are beginning to openly counsel Middle Eastern Arabs about the risks of marrying “too close to home”. There is a strong medical attitude to making genetic tests mandatory before marriage.

Al-Ghamdi (1991) reported that nowadays there are changes to the institution of marriage in Saudi society. The incidence of marriage among non-relatives seems to be growing in urban localities. The attitudes towards marriage among relatives have changed and new generations tend to practice exogamy. Al-Ghamdi (1991) reported that while polygamy (in which Muslim men are allowed, in accordance with the perception of Islam, to have up to four wives simultaneously), marriage among relatives, and very early marriage were common features in Saudi society in the recent past, the new generation seems to be in favour of abandoning them.

### 4.2.5. Importance of religion:

In the Saudi society where this study was conducted, religious belief encompasses the society’s value system and guides social behaviours (Al-Garni, 2000). Social relationship in Islamic societies usually stems from religious and cultural values (Al-Garni, 2000). It is essential to understand that one of the fundamental elements of the Islamic religion is the belief in God’s absolute decree, and the concept of predestination for both good and evil (Al-Kheraigi, 1989). Al-Awad (1997) reported that religion is a central component in Sudanese culture, playing a protective role that mitigates family malfunction and promote child psychological health. Religious beliefs have been the most important factor in helping families to accept disability (Akhdar, 1994). A religious family perceives disability as a test of their faith and as an act of God’s will (Al-Kheraigi, 1989). Disabled people themselves believe that strong faith in God helps (Alhammadi, 2000).

In religious societies, the important role of religious leaders and religion itself helps parents come to terms with impairment (Akhdar, 1994). Although the impact of religion on Arabic people is very strong in affecting the level of acceptance of having a disabled child, those parents still might experience stress and need counselling to cope with the difficulties of living with their child (Fouzan, 1986).

Regarding pain and illness, Muslims believe that pain and disease are trials sent by God to test the person's faith and ability to endure. He/she is rewarded to the extent of the patience and faith they demonstrate while living with pain. And suffering might sometimes also serve as a punishment of sin (Sachedina, 1999; Al-Jelani, 1987). However, this view is acknowledged as being difficult to reconcile in the case of infant and child suffering. Scachedina (1999) observed that some regard the undeserved suffering of innocent children as a warning or a test for parents, with the suffering of the children rewarded in the next world.

Some Arab physicians believed that Arab patients were more tolerant of pain than other populations and did not want or need as much analgesic as western patients (Viogtman, 2002). The purpose of Voigtman's study (2002) was to describe the Saudi, Qatif socio-cultural response to children with sickle-cell disease and pain. Significant outcomes of the project included descriptions of Arab Muslim children, parents, and community perspectives on chronic or ongoing pain. Thirty-nine participants, including children with sickle-cell disease and family carers were observed and interviewed during illness episodes. Results demonstrated that religious precepts drawn from basic Islamic teaching support both tolerance of pain and suffering, and the seeking of cures. Benefits of suffering of pain with patience include enhancement of the sufferer's, relationship with God, family and community. In addition, using caring and moulding responses, family and community members guide children to endure pain for its intrinsic spiritual and social benefit.

While it is acknowledged that Muslims should seek cures for illness conditions, the quest for such a cure must be balanced with a spiritual approach to pain (Voigtman, 2002). In Voigtman's study, 80% of patients, to some extent, agreed with the statement "Pain medicine should not be asked for until the pain is unbearable" (Voigtman, 2002, p.40).

In conclusion, it is an important part of the Islamic religion to combine a spiritual approach with medical treatment. Praying, reading the Holy Qu'ran, visiting the holy mosques in Makkah or Medinah, or any other kind of Islamic spiritual rites should be carried out while seeking medical help.

### 4.3. Disability in non-western societies, stigma and attitudes towards disability:

Social stigma and attitudes towards disability and disabled people should be taken into account when studying families of disabled children in non-western countries. Many studies have shown that non-western societies have different attitudes and a different degree of social stigma towards disability. For example, in Chinese society, having intellectually disabled offspring is regarded as a punishment for the parents' violation (e.g. dishonesty, misconduct, or filial impiety) of Confucian teachings. This view implies that these parents should bear the responsibility for their own misconduct, and no sympathy or support should be given to them (Yuk-Ki-Chen & So-Kum Tsang, 1997). The cultural stigma attached to having intellectually disabled children may have prevented these mothers from seeking assistance outside their families (Lin & Lin, 1981; Yuk-Ki-Chen & So-Kum Tsang, 1997). In Korean society, the negative attitudes and stigma the society attached to disability seem to contribute to the lower level of support that the mother receives (Shin, 2002).

In the Arab world, as part of their tradition, a typically developing (TD) child is viewed as a gift from God, whereas a disabled child indicates the failure and worthlessness of parents, especially the mothers (Bakhsh, 1987). Parents take pride in saying, “see how blessed and worthy I am” or “see how capable I am, see what I have produced” (Bakhsh, 1987). Many mothers of disabled children feel social rejection; others mourn the loss of the baby they had wanted; others are angry and bitter and seek the reasons for their misfortune and inadequacy (Bakhsh, 1987). Akhdar (1994) and Al-Hammadi (2000) reported that attitudes towards disability are very poor in Saudi society. All disabled children in Saudi Arabia are stigmatised in one way or another, but those with epilepsy, those who have drooling on account of cerebral palsy and those with the obvious faces of Down’s Syndrome experience particular stigma (Akhdar, 1994).

Al-Khateeb (1988) revealed that there is a strong relationship between parents’ attitudes towards their child and the child’s disability. Parents with disabled children show less positive attitudes towards their children than parents with typically developing children. Differences within the disabled sample in attitudes and social stigma depend on the type and severity of disability. Akhdar (1994) found that parents of children with any disability accompanied by epilepsy, seen as “the most stigmatised disability”, are more depressed than other parents.

Al-Marsouki, (1980) examined Saudi Arabian attitudes towards the blind, the deaf, and the intellectually disabled. The instruments used to measure these attitudes was the Attitude-Behaviour Scale for the Deaf, the Blind, and the Mentally retarded (ABC-DBM). Results showed that attitudes toward the ID are less positive than those towards the deaf and blind. Attitudes towards blind people were more positive than any other disability. Al-Muslat (1987) found that Saudi educators held positive attitudes towards the mildly disabled (e.g. poor-sighted, hard of hearing, and learning disabled) and the most negative attitudes were towards intellectually disabled and emotionally-disabled children. However, teachers of students with hearing impairments had more negative attitudes towards their students than did teachers of students with visual impairments (Bin-Batal, 1998). Down’s syndrome children have been traditionally kept in the “back room", removed from the public eye and considered a shame to their families (Bakhsh, 1987). The mildly disabled received the most favourable attitudes, whereas attitudes towards the severely sensorily disabled were more generally negative (Al-Muslat, 1987). Akhdar (1994) noted negative attitudes to speech problems and deaf children, especially boys. There is sometimes a failure to differentiate between the mentally ill and the mentally disabled, which is common even today in Saudi Arabia. The disabled child or adult is treated in the same way as the mentally ill. In most cases they are kept at home (Al-Kheraigi, 1989).

The tendency to hide the disabled person is common in Arabic societies (e.g. Al-Hammadi, 2000; Al-Kheraigi, 1989; Bakhsh, 1987). Most of these families think that the future of the girl's siblings is in jeopardy if it becomes public knowledge that their family has a disabled daughter (Al-Kheraigi, 1989). Similarly, Alhammadi (2000) revealed that some families hide their disabled relative because they fear that other families would not allow marriage with any other family member. The parents of disabled children are torn between their love for their children and their desire to protect the family name. Therefore, keeping the child hidden serves two purposes: on the one hand, the child is not pitied and made fun of by other people, and on the other hand, the family's name is kept up (Al-Kheraigi, 1989).

One of the common beliefs about disabled people is that a person with mental illness or intellectual disability or some forms of physical disability is possessed or attacked by evil spirits (Jinn) (Al-Kheraigi, 1989). This is especially true for those who have epilepsy (Akhdar, 1994). Another belief that is prevalent in the society is that of the evil eye. Unconscious envy is the power that can bring harm and damage to many things (Al-Kheraigi, 1989). These kinds of beliefs lead most families to seek support from traditional healers (El Hag El Awad, 1994).

Although health-care centres are readily available to the public, traditional healers, and folk medicine including the use of herbs and cautery [1] is widely used and practised (Al-Essa, Al-Mahaidib, & Al-Gain, 1997). Akhdar (1994) revealed that in his study, every family in Saudi Arabia with an epileptic child wished to conceal this impairment and to work closely with traditional healers in an attempt to get their own child back. They (traditional healers) currently provide most of the support families receive (El Hag El Awad, 1994). Akhdar (1994) suggested that since traditional healers have been shown to play such a key role, they need to be integrated into an ongoing programme of surveillance. They need training in the recognition of other impairments over and above those they already recognise well. They also need to have information on what medical and education services they can refer the family to when an impairment is diagnosed.

Although it has been reported that the disabled child can be the target of pity and humiliation by his/her peers and others (Al-Marsouqi, 1980; Al-Kheraigi, 1989), some studies revealed positive attitudes and social stigma in the Middle Eastern Arabic societies. Al-Kheraigi (1989) noted that disabled persons are not usually abandoned, tortured, or abused by their families or by the society. Although there is an intense fear of a child who has epilepsy, the child with developmental delay is seen as being nearer to God, and greater respect is accorded to mothers caring for a child with disability, and many families ascribe the impairment to the will of God (Akhdar, 1994). “the feeble minded” were considered by the public as having their minds resting in heaven while their bodies mingled with ordinary mortals (Al-Kheraigi, 1989). They attribute the impairment to the closeness to God (Akhdar, 1994).

In general, educators’ attitudes towards disabled people are highly positive (Al-Muslat, 1987; Al-Kheraigi, 1989). In addition, women tend to have more tender attitudes toward disabled children than men (Al-Marsouqi, 1980).

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[1] Cautery: a kind of holistic and folk medicine which can be defined as burning the surface of the body in order to destroy infection or stop a wound (Crowther, 1999)

Afroze (1978) (cited in Al-Marsouqi, 1980) attributed positive attitudes towards the disabled to Islam, which shapes believers' attitudes.

As a final point, the attitudes towards disability in all Islamic contexts were positive and especially towards the carers of disabled person. Still, attitudes in Arab societies in general and Saudi society in particular are still negative towards disabled people and to their families as well.

## 4.4. Family stresses in non-western societies:

### 4.4.1. Reaction to disability:

Research in western countries, as reported in Chapter 3, has consistently shown that the parents of disabled children experience higher levels of emotional, financial, and physical stress (e.g. Byrne & Cunningham, 1985; Singhi, Goyal et al., 1990). In spite of the differences between non-western societies in terms of family size, family structure, social stigma, attitudes towards disability, and the importance of religion, cross-cultural studies of families of ID children show similar findings. Parents of ID children experience high levels of emotional, financial, and physical stress in non-English speaking families from central America (Gallimore, Goldenberg, & Weisner, 1993) and Asian countries such as Japan (Mink, 1990), Sri Lanka (Nokapta, 1986), Korea (Shin, 2002), China (Singhi et al., 1990; Yuk-Ki-Chen & So-Kum Tsang, 1997), Bangladesh (Zaman et al., 1986) and Arab countries (e.g. El-Hadidi, 1994; Al Dawood, & Al-Bar, 1995).

Akhdar (1994), Bakhsh (1987) and Rabah (1986 ) reported that in Saudi Arabia reaction to disability is really very similar to other places. Shock, helplessness, shame, guilt, denial, defensiveness are some interpretations of reactions such as anger, stress, anxiety, and depression, as well as feelings of frustration and rejection of the child. Parents usually seek reasons for the problem, these include blaming fate, the Evil Eye, blaming themselves, or blaming possession by spirits. A common anxiety in families is concern for the child's future (Akhdar, 1994; Fury, 1994; Yuk-Ki-Chen & So-Kum Tsang, 1997). One of the most common reactions is confusion and uncertainty about what to do and how to cope (Bakhsh, 1987). Akhdar

(1994) revealed the greatest fear of having a child with disability is not the diagnosis but the associated treatment and rehabilitation. This result was from a large-scale prevalence study of 1,120 households with 2,696 disabled children which achieved a 90% response rate relating to 2,432 children. The author had many contacts with each family over the study period. These contacts ranged from accompanying the family to medical appointments, therapy and other sessions, to in-depth interviews. The total duration of contact with parents varied from 20 to 25 hours. Further information was obtained from key informants, teachers, children surveyed in the schools, grandparents, and 25 religious leaders (Imams).

Also other non-western studies revealed that Korean mothers are more stressed than American mothers because of the lack of informal support and the perceived quality of support, and American mothers depend on professionals more than Koreans (Shin, 2002). Moreover, Japanese families have higher levels of conflict, emotion, psychological problems, and get more stressed than U.S mothers (Shin, 2002).

Parents of disabled children go through many stages before they accept the case as fate (Al-Kheraigi, 1989). The negative factors working against acceptance include emotional exhaustion, denial, high visibility, too high expectation, too low expectation, negative attitudes (stigma) in the community, and overdependence on the mother or on carers (Akhdar, 1994). Al-Kheraigi (1989) revealed that generally, in Saudi society accepting disability is an acceptance of fate, which reveals the strength and dependence of the individual's belief in God's will.

### 4.4.2. Variability in family stress:

As in western studies, non-western studies reported that families' reaction to disability may vary. There are many factors that affect the level of stress faced by a family, such as the type of disability, gender of the child, age, type of support, appearance of behavioural problems, severity of disability and parent-child reaction.

**4.4.2.1.Type and severity of disability:** The type and severity of disability have been described as important factors affecting the family's level of stress. Bakhsh (1987) revealed that Down's Syndrome children were reported as less problematic than other ID children (Bakhsh, 1987). Visually disabled children were reported to be more accepted by parents than those with other disabilities, whereas ID children were regarded as being at the bottom of the scale (Al-Kheraigi, 1989; Alhammadi, 2000). El-Hadidi (1994) reported that families who have ID children experience the most stress, followed by families of children with a hearing disability, then families of children with physical disabilities, and lastly families of children with a visual disability. Akhdar (1994) reported that mothers of children with uncertain aetiology were significantly more likely to be dissatisfied than mothers of children where the diagnosis was known. In addition, the severity of a disability can influence a parent's acceptance of their child's impairment (Akhdar, 1994). The severely disabled child is perceived more negatively than the mildly disabled child (Al-Muslat, 1987).

**4.4.2.2. Age**: The age and gender of the child were reported to be important predictors of a family's level of stress. An older child was reported to be more stressful for parents than a younger child (Bakhsh, 1987; Khan, et al., 2000). Akhdar (1994) revealed that parental stress increases as a child grows older.

Older children are more stressful to their parents for many reasons (see Chapter 3). Al-Hammadi (2000) reported that more attention is paid in Saudi Arabia to disabled children than to disabled adults. In the case of children with physical disabilities, the physical demands of lifting become greater as the child gets older and heavier and parents (especially the mother) become less able to lift the child (Akhdar, 1994). Moreover, in Saudi society, when a child behaves as a child they are accepted as such until he/she suddenly looks like an adult, at which point people no longer accept him/her so well (Akhdar, 1994) and this might cause great stress for both parents. Also, in Saudi society there is a very abrupt gender separation at puberty. When the child (especially the boy) looks young, they can come and go amongst women and other children with no problems. However, as soon as he looks adult, this is not acceptable. This sudden change can be difficult for him as well as for the mother (Akhdar, 1994). On the other hand, Mirza (1993) reported that there are no differences between parents' attitudes to older and younger children with multiple disabilities.

**4.4.2.3.Gender:** Gender was reported as important in Arab societies. Arab families in general prefer sons for social, cultural and economic reasons (Al-Ghamdi, 1991). Also in Saudi Arabia, families prefer sons to daughters (Al-Said, 1988). It is believed that a son can protect and support his family as long as he lives, but a daughter will soon leave the family for her husband's house (Al-Said, 1988). Al-Ghamdi (1991) reported that it is a strongly held belief in Arab societies that children, especially when they are male, represent future economic security for a family. These cultures place a much higher value on male children than female ones. These cultural beliefs are considered to be a major motive for any parent to have at least one son. The majority of parents prefer to have sons rather than daughters (Al-Ghamdi, 1991). Nyrope (1984) (cited in Al-Said, 1988) argued that a woman's status depends ultimately on her success in producing sons for her husband's family; as a result mothers tend to favour their sons. The parents are known by the name of their child (father of) especially when the child is a male (Al-Ghamdi, 1991).

Cultural attitudes and stigma towards a child's gender may affect their attitudes towards the disabled child. Acceptance of a disabled male was reported to be easier than a female one for parents as well as for the public (Al-Kheraigi, 1989). Disabled females, in particular the intellectually disabled, are seen as an endless burden to the family, not only morally but also financially. The family tend to shelter and protect their disabled women twice as much as they would non-disabled women, to make sure that their reputation is not jeopardised and because they believe that they would be an easy target for sexual violation. They save her not only for her own sake and benefit, but also for the protection of the family honour. In general, these attitudes towards women are common regardless of their ability or disability (Al-Kheraigi, 1989).

Although these attitudes towards females in general and disabled females in particular are hated by the Islamic religion and there is an obligation in Islamic religion to treat males and females equally (Al-Ghamdi, 1991; Al-Kheraigi, 1989), it is still common for the attitudes towards a disabled female to be less favourable than to a disabled male (Al-Kheraigi, 1989). On the other hand, only one study (Mirza, 1993) has reported that there are no significant differences between parents' attitudes to males and females with multiple disabilities. For mothers, whether the child is male or female, are faced with equal concern about the future (Al-Kheraigi, 1989).

**4.4.2.4.Behavioural Disorders (BD)**: Mothers of disabled children with more BD experience more stress (Akhdar, 1994; Shin, 2002). Abu-Ali (1988), and Khusaifan (2000) showed that among Arab children there are significant differences in the BD of disabled children and TD children. Akhdar (1994) revealed that children with certain impairments are more likely to show behavioural difficulties than TD children. It is reported that BD are associated with family size, parents' education, birth order, social class, and presence of both parents in the family (Abolfotouh, 1997). As reported by Rutter (1989), single parents are more likely to have children with BD (Abolfotouh, 1997). Al-Awad (1997) reported that there is no difference between lower and higher-class families in respect of child BD. In addition, the different effect of parental religiosity on child behavioural problems was enormous. However, Abolfotouh (1997) reported that families in lower socio-economic classes were more likely to have children with behavioural problems than families in a higher socio-economic class.

Finally, a low level of parental education is significantly associated with an increase in psychological disturbance (Felemban, Hanif, & Al-Almaie, 1998). More shock and stress were reported by parents when the impairment was particularly stigmatised in the society (Akhdar, 1994).

Moreover, large numbers of children add more stress to the family (Al-Samadi & Al-Husain, 1996).

## 4.5. Importance of social support in non-western societies:

As in western studies, both formal and informal support have been reported as important to parents by their families and society. Psychological distress is believed to be greatest for individuals who are experiencing both a low level of support and a high level of stressful life situations (Al-Awad, 1997).

In parallel with the western findings, Al-Awad's (1997) research in Sudanese society reaffirmed the positive effect of grandparents in supporting the family. Moreover, Al-Awad and Sonuga-Barke (1992) reported that the Sudanese grandmother would be available to take over responsibility for the child and so provide the child with security. Grandmothers, along with other relatives in the extended family, might provide social support that reduces the risk of maternal isolation and depression, increasing parenting efficacy and leading to less risk of emotional and behavioural problems (Al-Awad & Sonuga-Barke, 1992). In China, mothers received support mainly from family members and training centre staff (Yuk-Ki-Chen & So-Kum Tsang, 1997). Korean mothers are more likely to rely on family members to help them take care of their ID child, whereas American mothers are more likely to depend on professionals (Shin, 2002).

In Saudi Arabia, family relationships are shaped by a strong cohesion (Al-Garni, 2000). In Saudi Arabia, extended families have always helped parents to look after their disabled child (Akhdar, 1994). Some neighbours and extended family members were shown to help more than others (Akhdar, 1994). Alhammadi (2000) reported that most parents have an informal support system, which is available when they need it and which is consistent with the Saudi family and national culture. These informal supports include emotional, transport, household duties, and financial support. Apparently, all these findings emphasise that the parents who receive help and emotional support from family members and friends were much more able to maintain a secure and affectionate environment for their children than those left to face difficulties by themselves (Al-Awad, 1997).

Formal support in most of the non-western studies has been reported to be less common than in western societies. In addition, families are not usually satisfied with what is provided for them. Bar (1983) reported that in Saudi Arabia there is no basic law relating to the education of the disabled. Moreover, in most Arab countries, few facilities are available to provide adequate services for disabled people (Al-Kheraigi, 1989).

Professional support is very important in Saudi Arabia, where parents have a negative view of illness and tend to overemphasise its extent (Bakhsh, 1987). However, there is not adequate formal support, such as formal organisations for parents of disabled children (Bakhsh, 1987). There is a strong need for health professionals involved in helping families of affected children to fully understand the social and the cultural milieu of the family (Akhdar, 1994).

Because there are no comprehensive services yet in Saudi Arabia for dealing with disability, parents experience many problems associated with the services when seeking advice about their children (Akhdar, 1994). Al-Hammadi (2000) reported many areas of weakness in formal support in Saudi society especially for people with physical disabilities. He reported that there are no agencies to provide services such as housing or training in how to use transport. There are no employment agencies to aid the disabled adult to find a job or to train them in an occupation. Most families were very dissatisfied with the lack of accessible housing. Although medical treatment is free, medical centres are not responsible for providing medical equipment, which is too expensive for most disabled people. Public transport such as buses are not suitable for disabled people and other transport services are limited. Al-Essa et al. (2000) reported that health care providers have not done enough in educating parents. In general, Saudi families expressed a need for more formal services (Akhdar, 1994). Only medical rehabilitation centres were reputed to have an adequate provision of rehabilitation services (i.e. the military hospitals), however, the general Saudi population cannot receive any service from these hospitals. Other medical rehabilitation centres need more equipment.

The importance of formal support has been cited by other non-western families. In Korea, mothers of ID children have smaller formal support networks than American mothers (Shin, 2002). Professionals were less available in Korea because professional services are still in the early stages of development. In China, formal support such as professional support and self-help groups are perceived of as less common sources of support (Yuk-Ki-Chen & So-Kum Tsang, 1997). In India, formal support has also been reported as being needed by most parents (Peshawri, 1998). These results also indicate that to some extent, non-western societies receive less formal support than is reported in the western literature (see Chapter 3).

## 4. 6. Path model of this study:

Before starting to introduce the current study a brief review of the role of coping, social support and family structure in mediating/moderating the link between child disability and maternal well-being (Figure 10).

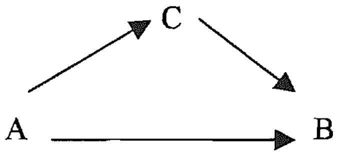
Before explaining the mediating and moderating roles of coping and social support, it is important to present simple definitions of the meaning of moderator and mediator. Barron and Kenny (1996) defined them as following:

1. Moderator variables: "In general terms, a moderator is a qualitative (e.g. sex, race, class) or quantitative (e.g. level of reward) variable that effects the direction and/or strength of relation between an predictor variable and criterion variables" (p.1174).
2. Mediator variables: "In general, a given variable may be said to function as a mediator to the extent that it accounts for the relation between the predictor and the criterion. Mediators explain how external physical events take on internal psychological significance. Whereas, moderator variables

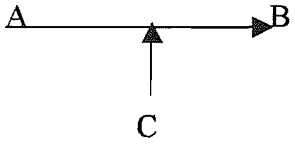
specify when certain effects will hold, mediators speak to how or why such effects occur" (P.1176)

The role of coping and social support in the literature was not clear. This was because most of the studies examined either the mediating or moderating effects of coping and social support. Furthermore, the difference between mediation and moderation in the disability literature is not always clear. Baron and Kenny (1986) clarified that a mediator specifies how a given effect occurs, whilst a moderator specifies the conditions under which the effect occurs; the conditions under which the size and direction the effect vary (see Figure 10).

Figure (10) Path diagrams for mediation and moderation effects



Mediation



Moderation

In the literature both mediation and moderation have been used to describe the impact of coping on the relationship between stressors and outcome. For example the process model of stress and coping (Lazarus & Folkman, 1984) stated that the process of coping mediates the effects of stress on an individual's well-being. In addition, Thompson et al. (1993) argued that coping mediates the illness-outcome relationship. Regarding parents' involvement in programs for young children with disabilities, Payne and Stoneman (1997) also stressed that coping played a mediating role between family functioning and parental involvement. Even in studies recruiting participants from other populations, Benight and Harper (2002) showed the mediating effect of coping between acute stress response and 1-year outcome following two natural disasters. Other studies (Wallander et al., 1989) argued that coping moderates the effect of a child's physical disability on individual adjustment.

Regarding social support, both mediator and moderator influences were examined in studies of parents of children with disabilities as well as with other populations. For example, Dunst, Trivette and Cross (1986) examined the mediating influence of social support in a study of parents of children with ID, physical disabilities and developmental risk. Results showed that social support has a mediating effect in parenting well-being. Moreover, the mediating effect of social support were not tested only in parents of disabled children but it was also tested in disabled people. Allen, Ciambrone and Welch (2000) showed that instrumental and emotional support were key in mediating depressive mood in young people with disabilities.

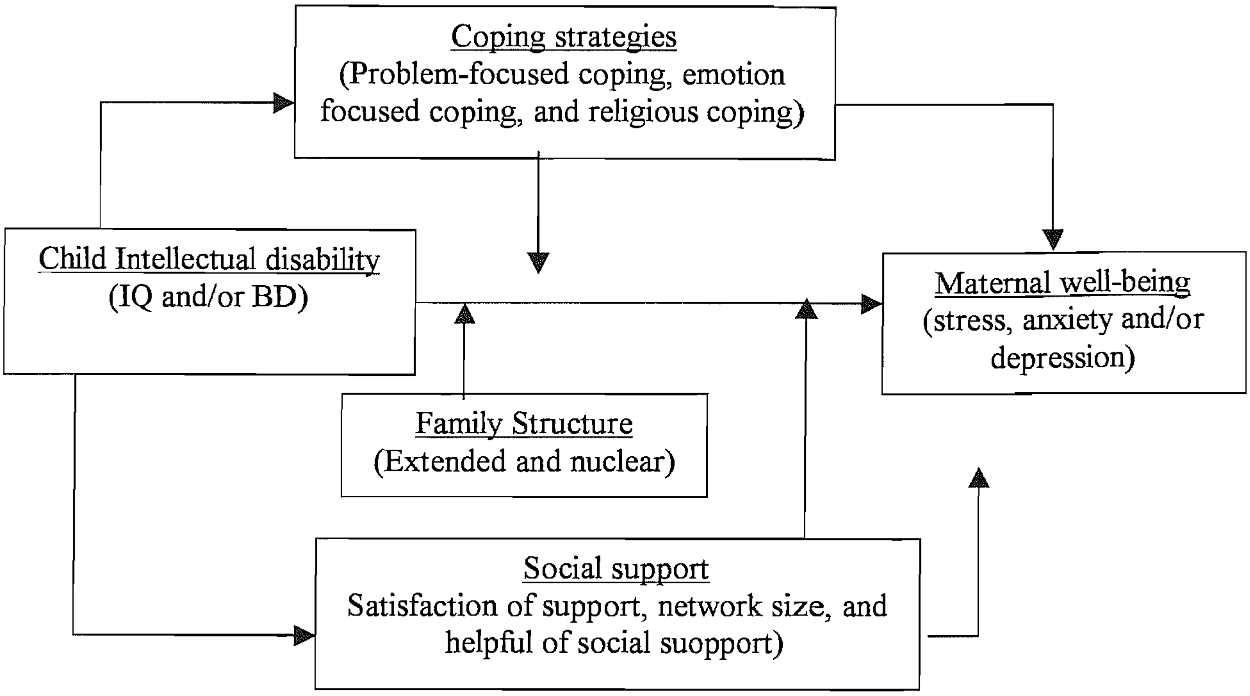
In contrast, other studies have showed the moderating role of social support. For example, Hastings (2003) showed that social support functioned as a moderator of the impact of autism severity on siblings' adjustment rather than a mediator or compensatory variable. The moderating effect of social support was confirmed when used with other populations. For example, social support moderated the influence of the exposure to stressful life events on depression among older adults (Chou & Chi, 2001). In addition, Ergh, Rapport, Coleman and Hanks (2002) showed a powerful moderator effect of social support when they examined predictors of family dysfunction on carer's distress among people who sustained a traumatic brain injury.

Social support was said to moderate and sometimes mediate the effect of stressors, however the confusion about the meaning and proper testing of these predictions was evident in much research examining both mediating and moderating effects of social support on maternal outcomes. According to Vaux, (1988) diversity of measures, particularly in the absence of a theoretical framework for sorting themes, makes synthesis of research findings difficult.

Vaux (1985) stressed that when multiple measures of support were used within studies, they often yield inconsistent results. Because social support has many aspects, such as network size or number of sources of support, level of helpfulness of support and satisfaction of support, we believe it is very important in this study to cover these three aspects of social support rather than just focusing on one aspect of support which might be the main reason for diversity in the previous studies' results. Although Vaux (1985) emphasised that in the short run, studies employing multiple measures often contribute to the confusion, but in the long run they were critically important in generating and testing more sophisticated models of social support and distress. That was the main reason for using two instruments in testing social support in this study. The Social Provision Scale (SPS) were chosen to test the support satisfaction while the Family Support Scale (FSS) tested the number of source of support and the level of helpfulness of social support. Each one of these Social support phases was tested in independent regression analyses for different maternal outcome (stress, anxiety and depression). In addition, when FSS were recoded to 1 and 2 (not available and available) the test used to measure number of source of support and reported in tables as (FSS2).

For the family structure (extended and nuclear), Figure (11) hypothesises the moderating effects of family structure on child ID and maternal well-being (stress, anxiety and depression). Although few studies in the literature mentioned the different effects of nuclear and extended family on maternal well-being (eg. Shah, Sonuga-Barke, 1995; Sonuga-Barke, Mistry & Qureshi, 1998) family structure has always been mentioned as a moderator between stressors and maternal well-being which was examined in this study as well.

Figure 11: Path model of the current study



Having presented the similarities and differences between western and non-western cultures, it is essential to present a model which can be applied to non-western cultures (see Figure 11). Firstly, this model shares the major paths of the models presented in Chapters 2 and 3. Here, we predict that the disability (IQ and/or BD) is the independent variable which has a direct effect on maternal well-being (stress, anxiety and/or depression). Coping, family structures, social support play a moderating or mediating role between the child's ID and mother's stress.

This model has presented and hypothesised some new variables, which were not present in the previous models (see Chapter 2). For example, family structure (extended or nuclear) was not included in any of the western models. Moreover, all of the important demographic variables were controlled for. Some of these demographic data which are important to focus on when studying Arabic and Islamic culture such as polygamy, were not mentioned before in any of the previous study. In addition, stress was usually presented as an outcome, but we believe that the outcome is not only stress but a general maternal well-being (stress, anxiety and depression). For these reasons we found it essential not to copy any of the models in the literature, but to create our own model which can be applied to Arabic culture in general and in particular to Saudi culture.

## 4.7.Conclusion:

This chapter reviewed the non-western literature, especially as related to Saudi and other Arab societies, on the psychological impact on parents of children's developmental disabilities.

Similarities and differences between families in these two broadly defined cultural settings have also been reported. Despite the numerous differences between western and non-western societies in family size, family structure, marriage system, and stigma and attitudes towards disability, non-western studies have in large part replicated findings on parenting outcomes with a disabled child in western settings. Reactions reported in these studies include shock, helplessness, shame, guilt, denial, anger, stress, anxiety and depression (e.g. Akhdar, 1994; Bakhsh, 1987).

In addition, the non-western studies have reported variability in response and that not all families react similarly to the crisis. The level of stress experienced by families of disabled children may vary according to many factors, such as the gender and age of the child, the type of support provided to parents, the manifestation of child behaviour problems, and the severity and type of disability

These findings have led us to an important conclusion, that in spite of all the differences between non-western and Islamic, Middle-Eastern societies, parents of disabled children to a large extent seem to share the same outcomes as described in the western literature. This means that theories (such as Lazarus and Folkman, 1984) based in western cultures (specially US and UK) might be appropriate to non-western societies if we take into account certain cultural differences and cultural features or characteristics. Hence, we believe that all the models presented in Chapter two can be applied to Arabic, Middle-Eastern studies if we put in mind the need of some modification of certain mediators and/or mediators presented in the path model of this study (see Section 4.6).

# CHAPTER 5

# THE KINGDOM OF SAUDI ARABIA: BACKGROUND

## 5.1. Introduction:

The focus of this study is stress and coping in mothers of disabled children and the social support available to them. In order to enhance the non-Saudi reader's understanding of the study, it is necessary to present a brief orientation to Saudi Arabia, its people, law, culture, education and health systems, and disability in Saudi Arabia. A brief overview will also observe the two cities (Makkah & Jeddah), from which the study population have been selected.

## 5.2. History:

Saudi Arabia was and still is the focus of attention, because of its location as a religious centre of all Muslim people around the world who direct themselves towards the holy mosque in Makkah five times a day and millions of Muslims visit the holy cities every year (Al-Ghamdi, 1991).

In 1924, King Abduaziz Bin Saud unified four regions in the Arabian peninsula, Najd, Alhijaz, Assir, and Al-Hassa. In 1932, modern Saudi Arabia was founded and given its name the 'kingdom of Saudi Arabia' by King Abdulaziz.

Saudi Arabia is a unique model of a growing nation. Within three decades, it has developed from 18th-century conditions to 20th-century conditions. It has witnessed enormous changes (Alsaif, 1991; Al-Hammadi, 2000). All of the Saudi population speak Arabic and the predominant religion is Islam, which has influenced the shaping of common culture and values (Al-Marsouqi, 1980).

## 5.3. Geography:

The Arabian Peninsula has an area of about one million square miles. Saudi Arabia with an area about 870,000 square miles, occupies the largest part of it; about 80% (Al-Marsouqi, 1980; Akhdar, 1994; Bin-Battal, 1997; Europa World Year Book, 1997). It is roughly one-third the size of the United States (Al-Marsouqi, 1980).

The kingdom of Saudi Arabia is bounded on the north by Jordan, Iraq and Kuwait, on the south by Oman and Yemen, on the east by the United Arab Emirates, Qatar, and the Arabian (Persian) Gulf, and on the west by the Red Sea (Abdrabboh, 1984) (see Figure 12).

The land is mainly desert and only 1% is cultivated. There are no permanent rivers (Al-Marsougi, 1980). Except for the south west part (Asir province), the average rainfall throughout Saudi Arabia is generally very low, about six inches or less per year (Bin-Battal, 1997; Al-Ghamdi, 1991 ; Al-Marsouqi, 1980)

The Arabian Peninsula has a particularly inhospitable climate. Land in the kingdom is generally arid with a desert climate. With an average temperature of 90 degrees Fahrenheit in the summer, and 15 degrees Fahrenheit in the winter. However, the temperature is low in the mountain areas in both summer and winter. In spring and during the first part of summer winds are very harsh (Al-Ghamdi, 1991; Al-Marsouqi, 1980; Nyrope, 1984,).

Figure (12): Map of the Kingdom of Saudi Arabia

## 5.4. Islam and law in Saudi Arabia:

For all Muslims, including Saudis, Islam is way of life which cannot be separated from daily life (Al-Hammadi, 2000). Saudi Arabia has long been the holy place for all Muslims because of the location of Makkah and Medina, the two Muslim holy cities.

as prayers, fasting, pilgrimage, and so forth, and the secular, such as social, political, economic, etc. Hence, all social manners and behaviour have to be guided and governed by Islam, such as relationships among people, personal status (marriage, divorce, etc.) and sexual behaviour (Al-Ghamdi, 1990).

The law of the country is the Islamic law or the "Sharia" which is considered to be the source of all legislation and is the basis of the legal system of the kingdom (Al-Ghamdi, 1990; Akhdar, 1994). The Holy Qur'an is considered the main source of the constitution of the kingdom (Al-Hammadi, 2000). Hence, Saudi Arabia is deeply Islamic, a religion which is the source of all legislation and regulations of the entire country.

As regards to disability, it is believed from an Islamic point of view that the person who is patient and endures suffering will be rewarded in the hereafter (Alshaia, 1997). The disabled people and their families in Saudi Arabia view the disability from an Islamic perspective. A disability or sickness is considered to be a test from God to determine whether the individual is patient, believes in their destiny, and thanks God for whatever is sent to him/her (Alshaia, 1997). Al-Jelani (1987), a surgeon practising in Jeddah, Saudi Arabia, indicated that pain and disease are trials sent by God. The purpose of such trials is to test Muslims' faith and ability to endure. Muslims are also rewarded to the extent of the patience and faith they demonstrate while living with pain and disease.

In brief, Islam has influenced Saudi public and private life and is considered to be the basis of law and regulations. It also manifests itself in many ways in the individual's daily life.

## 5.5. The Saudi family:

The family is the fundamental and most important element in the social structure of Saudi society and it is also considered the basic resource for all the social characteristics of the people in society (Al-Ghamdi, 1990). To gain a clear picture about the disabled in Saudi Arabia, one must understand the structure and function of the Saudi family, which is highly regarded in the country as a social unit (Al-Hammadi, 2000).

In this part we will discuss some of the Saudi family characteristics such as family structure, the marriage system (age, polygamy) and family size.

### 5.5.1. Family structure:

In the past the Saudi Arabian family was in all cases large and extended. This was the ideal type for Saudi people. The traditional Saudi family is based on an extended family unit which consists of husband, wife, their children, and their married sons with their wives and children as well as the husband's parents (Al-Hammadi, 2000). This extended family consisting of more than one generation is headed by a senior male member (Al-Ghamdi, 1990).

The oil era in Saudi Arabia marked the beginning of transformation from a simple, primitive society living in a group of extended families to an industrial, modern, and complex one, where the economy became specialised, and nuclear families were emerging as the dominant pattern, particularly in urban areas. (Al-Ghamdi, 1990). Hence, the Saudi family is a result of modernisation and urbanisation, that is, as families have moved from small villages to larger cities, the family unit has become somewhat smaller.

Al- Gamdi (1990) mentioned that the extended family has been substantially weakened and the isolated nuclear family has emerged as the dominant type in contemporary society. People become independent and therefore no longer need to depend on each other as they did in the past. On the other hand, Al-Saif (1991) reported that, although in some cities the extended structure has begun to change to the nuclear family, this structure is still characteristic of families in Saudi rural areas. According to Voigtman's view (2002), in Saudi Arabia, the nuclear family structure is most often observed, particularly in urban areas. However, multiple patterns of family living are in evidence with, for example, long-term "visiting" of elders, aunts, and uncles.

Sharawi, (1987) pointed out that at present, a high proportion of married women did not wish to live with their husband's parents at all. Initially a few of them lived for a short time in their household. Al-Juwayer (1984) also indicated the majority of respondents of his research sample belonged to nuclear families. However, some studies considered the Saudi nuclear family is not the same as a nuclear family in western society. They believe that in Saudi Arabia it consists of husband, wife, their unmarried children, and the husband's parents (Al-Hammadi, 2000). It was found that 82.6% of the families in Saudi Arabia were nuclear families (Alturaiki, 1997). However, in the current study we include only the parents and their children without the husband's parents in the nuclear family category.

This change in family structure (extended-nuclear) has not affected the family role toward children or parents, or family duties and ties. The family's kin relationships are still maintained and are strong. The contact between family and kin is still maintained and practised, despite the fragmentation of the extended family. Family members also keep visiting each other and support each other any time they need to. The Saudi family, whether extended or nuclear, is still characterised by dynamic physical and psychological contact between members of the family (Al- Ghamdi, 1990; Al-Hammadi, 2000; Voigtman, 2002).

### 5.5.2. Marriage system:

The institution of the family from an Islamic point of view must be built on marriage which is considered a very important part of the faith, and one of the motives and purposes of marriage is religious. From an Islamic point of view, sex has a sacred function and Islam places a great emphasis on prolificacy and Muslims are encouraged to procreate (which must be undertaken according to religious proscription and prescription, Al-Ghamdi, 1990).

From an Islamic point of view marriage is the rule for every man and woman to fulfil and it is the only legitimate context for sexual gratification. Thus Islam encourages people to get married.

Marriage in Saudi Arabia was and still is carried out according to Islamic teaching and regulations. Therefore, no changes have taken place in the marriage formalities, but changes might be occurring or emerging in the mechanism of marriage, such as age at marriage, mate selection, marriage to relatives, and so forth.

**Kinship marriage:** Because the high cost of marriage makes it difficult for a person to marry without the support of parents or relatives, prearranged marriages (even to non-relatives) are common in Saudi Arabia (Alsaif, 1991). However, Saudis prefer to marry their own relatives within one family unit (especially cousins) because they consider such a marriage a guarantee of good stock and better connection for both groom and bride. In addition this marriage will maintain the family unit and keep the relationship between the members of the family strong and intimate. This kind of marriage has been considered very desirable and the most common type in the country. It is considered most preferable from a cultural and traditional (not a religious) point of view. (Al-Ghamdi, 1990).

Kinship Marriages are still to be observed in Saudi society, and the family continues to be distinguished by strong bonds between its members and old traditional intimate relationships between people still exist and are not yet dissolved (Al-Ghamdi, 1990). However, another study carried out in Saudi society indicated that marriage among relatives is declining generally, highlighting the fact that it is declining faster in urban areas, especially among educated people of both sexes, than in rural areas (Al-Ghamdi, 1985). People should be educated and informed by the media that relative marriage is not preferable by the Islamic point of view, because of the probability of having children suffering from genetic diseases. For example, Saudi Arabia is reported to have the highest percentage of people suffering from sickle-cell anaemia and Thalessemia, especially in the eastern and northern part of the country where the relative marriage is preferable by most of the families (Taibi, 1997).

**Age:** The age of marriage in Saudi Arabia is lower than in some other countries. Islamic law does not specify any particular age of marriage. However, Islam encourages people to marry early when they become fertile, so the period of reproduction will be lengthened. It also ensure that they will not have any illegal sexual contact outside marriage (Al-Ghamdi, 1990).

In Saudi Arabia (before the socio-economic changes) people used to marry at an early age, so boys used to marry at the age of fifteen or sixteen and sometimes even earlier, and girls used to marry at the age of twelve or thirteen, but in any case girls used to marry before reaching the age of fifteen (Hamdan, 1985).

The age of marriage has been rising in all Arab countries, including Saudi Arabia. The age at marriage in Saudi society (after the massive development took place) has changed for both sexes (Al-Juwayer, 1984; Bagader, 1984). The age at marriage, especially for girls, varies from region to region. In the southern and northern regions, which are considered to be rural and Bedouin areas, girls marry at an earlier age than in the eastern and western areas, which are considered urban (Al-Ghamdi, 1985). Women nowadays are not anxious to get married before they have completed their education or embarked on a career.

**Polygamy:** Another issue in the Saudi family is polygamy, which is "the practice of marriage of one man to two or more women" (Marshal, 1998).

Marrying more than one wife is not the usual type of marriage in Islam, but Islam takes into account different situations and circumstances where it is necessary for a man to have more than one wife (Darsh, 1980). Four wives at a time are allowed by Islamic law but such polygamy has been restricted since there must be impartial treatment for all of them. That means the man must treat all his wives equally in everything (Al-Ghamdi, 1990) which is considered difficult. The practice of polygamy has been declining in Arab societies, including Saudi Arabia, over recent years. In the past, polygamy was more popular in rural areas than in cities and it has indeed become rare, especially in cities (Al-Ghamdi, 1990). Another study indicated that the negative attitudes towards polygamy is growing rapidly among the younger generation or women: "many women reported that they would separate from their husbands if it happened to them" (Al-Suwaigh, 1989, p.75). Even so, it is a part of the Islamic religion and it will remain permissible in society.

**Family Size:** Family size in Saudi Arabia is considered to be larger than in other societies. Urbanisation, movement and the transformation in the economic system have led to noticeable reduction in family size. The overall size of the family is still declining and people are tending to control the number of children they have (Al-Ghamdi, 1990). Based on a report from the National Research Project on Disability and Rehabilitation (Alturaiqi, 1997), nationally, the average family size is 7.64 members; rural families average 7.85 members, and urban families average 7.3 members, which is still considered to be a large family.

To sum up, the transformation in the structure of the Saudi economy has exerted a great influence upon the social life, however, it has not deeply affected Saudi households and families, although the influence is more obvious in urban families.

## 5.6. Disability and disabled people in Saudi Arabia:

During the 1980s and 1990s, more attention was paid to the disabled people in Saudi Arabia because of the United Nation (UN) declaration that 1982-1992 would be the decade of disability. During this period governmental services to the disabled increased, also many non-profit organisations in Saudi Arabia were established (Al-Hammadi, 2000).

In Saudi Arabia as in other developing countries in the world, it is difficult to accurately estimate or describe the disabled population. Alturaiki (1998) reported that knowledge about the field of disability and rehabilitation is inadequate in Saudi Arabia, and in the absence of any estimation of the numbers of children with disabilities, an attempt is made to approximate their numbers over the different categories (Alturaiqi, 1998).

There are no accurate statistics of the disabled in Saudi Arabia, for example, the estimation according to official percentage the Ministry of Labour and the World Health Organisation (WHO, Social and Development Consultant Research Centre, 1993) was 1%. Alturaiqi's (1998) estimate was 3.75%, and Alswaket, (1993) put it at 5.42%. According to the Ministry of Labour and Social Affairs 5.42% is recognised officially by them (Social and Development Consultant Research Centre, 1993), the same percentage (5%) is often used in social studies conducted in Saudi Arabia (e.g Alhammadi, 2000). By the year 2006, according to Europa (1997), it is expected that the Saudi disabled population will be 1 million.

People with a physical disability represent a majority of the disabled population in Saudi Arabia (60%), ID people are second (20%), followed by people with hearing and/or visual disabilities (10% hearing disability and 10% visual disability) (Hammadi, 2000). On the other hand, according to Alturaiqi (1997), the results of a study of 10,232 Saudi families living in several Saudi cities or villages, were that 33.6% of the whole disabled population have a physical disability, 29.9% have a visual disability, 13.4% have a speech disability, 10.7% have a hearing disability, 9.7% are ID, and 2.7% have a social or psychological disability. According to Alturaiqi (1998), some types of disability are not counted in Saudi Arabia, such as emotional disturbance people.

Many free services are offered to the disabled: medical, financial, and psychological care. For example, the Ministry of Labour and Social Affairs gives financial help in the form of monthly grants to enable people to be independent of their families (Al-Marsouqi, 1980). According to the Ministry of Information (1999), 43457 disabled people, living with their families received the equivalent of 52 million U.S dollars in 1995. However, Sofi (1992) found that only 23,018 disabled Saudis received any type of benefit from private or public agencies and organisations. In 1993 the number increased to more than 40,000 (Social and Development Consultant Research Centre, 1993) which is an indication of the increased attention to disability in Saudi Arabia.

Many other studies have proved that the disabled services are not adequate for the number of people involved and, although there is a dramatic increase of disabled recorded in Saudi Arabia, few of them have received services through public or private organisations (Al-Hammadi, 2000). In 1997, the number of disabled who received any type of direct or indirect services in Saudi Arabia was estimated to be 59.780, which means that only 44% received services and 56% did not (Alturaiqi, 1997). Alturaiqi (1997) found that the disabled have difficulty accessing either public or private services. Many reasons were mentioned for the services not being used. 25% because of the location of the service provider was too far away, 24% did not mention any reason, 20.6% because the services were bad, 5.3% because of language barriers, 3.9% because the services were expensive, 3.5% because of inadequate education of the disabled, and 1.7% because of inadequate training in the use of disability equipment. According to a study by Akhdar (1994) hospital data showed that the majority of disabled children presenting for rehabilitative care from the south west province of the kingdom (which is likely to give an erroneous impression of prevalence) indicated that there has been poor coverage of services in the south west of Saudi Arabia until recently.

To sum up, the insufficient or inappropriate services might arise from the high yearly increase of the Saudi population (see Appendix 10). Moreover, the information on which to base a valid judgement of the medical needs of the kingdom's population is presently and out of date (Akhdar, 1994).

## 5.7. Health services in Saudi Arabia:

Health services in Saudi Arabia have made great progress in recent years, resulting in an improvement in the health standard of the population, notably in the areas of immunisation, endemic diseases control and improved access by all population groups to health care facilities (Akhdar, 1994). An example of the improvement in health care in the kingdom is the number of hospitals. The numbers of operations between 1970-1990 increased by 243% and the number of hospital beds by 337% during the same period, the number of primary health centres increased, by 217%. (Akhdar,1994). On the other hand, there is still lots needed to be done in the field of health education services. For example, a study has been done in King Faisal Hospital and Research Centre in Riyadh recruiting 300 mothers showed that 95% of women do not take Folic Acid before or during pregnancy which causes an increase in births of children with spina bifida (Riyadh Daily News, 2003). Another study showed that Saudi Arabia reported to have the highest percentage of people suffering from sickle-cell anaemia and Thalessemia, especially in the eastern and northern part of the country where the relative marriage is preferable by most of the families (Taibi, 1997).

These studies indicate that there is an improvement in health services like the numbers of hospitals, hospital beds, or number of qualified staff. However, health education still needs a lot to work on. Recently, the government started to enforce medical examination before marriage in order to find out the genetic disorders in couple's families. Still, these medical examinations are not considered to be a kind of education for people.

## 5.8. Education service system:

Education in Saudi Arabia is an important factor in the study of disabled people and their families. It is obvious that one of the major factors influencing social change in Saudi society is the expansion of the education sector.

Before the foundation of Saudi Arabia in 1932, education was provided by a few schools which served a limited number of students (Bin-Battal, 1998). After 1932, the development of education was rather slow under the Directorate of Education and only a few students were enrolled at the schools available at that time (Al-Marsouqi, 1980).

Because education is not compulsory, there has been a dramatic increase in illiteracy in the kingdom. In 1962, it was estimated by UNESCO (as cited in Europa, 1997) that the rate of illiteracy was 97.5% for adults compared to 37.2% in 1995.

The modern huge expansion of education was started by economic development plans in the country. In order to solve the illiteracy problem, the government supports free education that is provided throughout the country for elementary, secondary, and higher education. In addition, the government supports higher education by giving college students an allowance to attend school (Al-Hammadi, 2000). In 1997, the Saudi government allocated 30% of its total annual expenditure to education (Europa, 1999).

The philosophical foundation of education in Saudi Arabia centres on Islam. The system's objective is to maintain the religious and moral values of Islam and religious education is an essential element in the curriculum.

## 5.9. Special education system:

The services available to disabled people in Saudi Arabia are provided through several ministries and non-profit organisations. Four agencies supervise the special education programme in the kingdom. The Ministry of Education, the Presidency General for Girls' education, Ministry of Labour and Social Affairs, and the Ministry of Health are responsible for providing special education services. Each agency provides services according to the disabled condition, gender, age, and type of service that are needed (Ministry of Education, 1999).

The birth of special education in Saudi Arabia occurred in 1958 through an independent effort by a devoted Saudi who had studied the Braille system in Iraq at that time. On a personal basis, the blind person started teaching other blind individuals at his home. Then the Ministry of Education provided him with the facilities for educating a hundred blind students in special evening classes in one school in Riyadh (Bin-Battal,1998).

The results of this attempt were good and two years later in 1960, the Ministry of Education adopted special education, incorporated it into a programme which was expanded to become the first institute for training of the blind, a day school called "the Institute of Light for Education and Training of the Blind in Riyadh". Making the official beginning of special education in Saudi Arabia in 1960 (Ministry of Education, 1999).

In 1964, the ministry established two institutes for the education of deaf children "the Institute of Hope for Boys and Girls in Riyadh", and the first institute for the ID (i.e., mild disabilities) was established. By that time there were already five institutes for the blind in the country (General Secretariat for Special Education, 1992). In 1971, the first institute for the training and care of intellectually disabled boys and girls was opened in Riyadh. By this time the number of institutes in the kingdom had reached eleven (Akhdar, 1994).

In 1972, the Ministry of Education made a resolution to found the first administration of special education to encompass the responsibilities of planning special education programmes and supervising their progress. The administration was promoted to the level of general directorate, with specialised departments and was named "The General Directorate of Special Education Programme" (Hamdan, 1980; Hardy, 1983).

We will focus in this section on the Ministry of Education because the sample for the current study has been selected from its institutes and schools. The ministry is responsible for offering educational programmes to school-age students who are visually disabled, hearing impaired or intellectually disabled as well as the programme for students with learning disabilities.

Until 2001 the disabled institutes were separated on a gender basis under two agencies, the Ministry of Education and the Presidency General for Girls' Education. In 2002 the latter was incorporated into the Ministry of Education. Hence, both sex institutes now are under the ministry of education. However, single-sex institutes still exist for all kinds of disability. Two basic types of courses are offered to disabled children: academic and vocational.

The services provided by the Ministry of Education are only provided to three categories: visually impaired, hearing impaired, and intellectually disabled children. These services have been provided through three different types of institute:

1. **Alamal Institutes "Hope Institutes":** for people with hearing disabilities. These institutes provide educational, cultural and rehabilitation programmes for both males and females. They provide elementary, intermediate and high school programs.

There are 50 institutes and programmes in regular schools in the Kingdom (37 for males & 13 for females); eighteen institutes for male and 19 programmes in classes in normal schools. For females, there are only 13 institutes distributed about the kingdom (Almaghlooth, 1999).

**2. Alnoor institutes "Light Institutes"**: for people with visual impairment. They provide educational, cultural, and rehabilitation programmes for both males and females at elementary, intermediate and high school levels. There are 22 institutes and classes in regular schools (17 for males and 5 for females), ten programmes in regular schools and 7 institutes for males. For females, there are only 5 institutes distributed among the kingdom's large cities (Almaghlooth, 1999).

**3. Educational institutes for intellectually disabled children:** these institutes provide the same services as the previous two, but only preliminary and elementary levels for students with an IQ of 50-75. The more severely disabled students are segregated into different residential institutes. There are 60 educational institutes and classes in regular schools (52 for males and 8 for females). There are 9 institutes and 43 programmes in regular schools for males. Moreover, there are only 8 institutes for females located in different cities of the kingdom (Almaghlooth, 1999).

In addition, there are eighteen non-profit organisations caring for the disabled. Some of these organisations have many branches in various cities all over the country. It is worth mentioning that, unlike the governmental institutes, the non-profit institutes do not separate male and female children. In addition, It is obvious that the percentage of male institutes is much higher than those for females which is inconsistent with the percentage of disabled males compared to disabled females in the population as a whole.

There is some critisism of the special education system in Saudi Arabia. In Akhdar's (1994) view, the ministry has developed the system of documentation and information flow poorly. Most of the available information rests in the files of high-ranking officials. On the other hand, Al

Hammadi (2000) pointed out that these institutes are not evenly distributed throughout the different regions of the country. 32% of Ministry of Education institutes are located in the western region of the country, 25.4% in the middle region, 23.4% in the eastern region, 10.7% in the south region and 5.5% in the north. (see Figure 12 for a map of Saudi Arabia). This geographic distribution is not consistent with the population and needs. For example, the city of Hail, located in the north of Saudi Arabia, has more than 27,000 disabled, but there are no institutes in this city. In comparison, there are only 3,200 disabled in Medina City, but five Ministry of Education institutes. In addition, the rate of illiteracy among the disabled in Saudi Arabia is still extremely high, 69% in 1997 (Alturaiqi, 1997).

## 5.10. Makkah and Jeddah (brief overview):

The western region where the cities of Makkah and Jeddah are located is the most urbanised and populous region in the country (Al-Dosari, 1983).

Makkah is considered one of the western region areas, which consists of many cities and villages of which Makkah and Jeddah are the two main ones. Firstly, Makkah is considered one of the most important cities not only in Saudi Arabia but also in the whole Islamic world because it is the location of the Holy Mosque and the other holy places.

On the other hand, Jeddah is located on the Red Sea in the western region of Saudi Arabia and is the crossroads leading to the Muslim holy cities, Makkah which is 75Km east of Jeddah and is where the grand mosque is located in Medina City which is about 400Km to the south. Jeddah is the centre of industrial activity in the western region. 30% of government project investment was undertaken in the city during the 2nd and 3rd five-year development plans (Al-Ghamdi, 1990). Therefore, about 80% of the industrial activity is located there (Al-Hamdan, 1987). Jeddah is now the largest, busiest and fastest growing city in the region, followed by the holy cities of Makkah and Medina (Al-Ghamdi, 1990).

It is worth mentioning that these two cities are considered to be the cosmopolitan cities in the kingdom with many people from different tribal and non-tribal roots living there. There are many Saudi people living there with roots in different countries. Because of the job vacancies in these two cities many people from all over the country stay in Jeddah or Makkah. In addition, because of the pilgrimage some people who came from outside the country preferred to stay in Makkah and by now they have Saudi citizenship. Hence, we believe that to a large extent, these two cities might be the best placed to study the diversity of the Saudi population.

These two cities have been chosen to represent the Saudi population for many reasons as follows:

1. Large population, which means a large intellectually disabled population.
2. Many governmental and non-governmental institutes that can help recruitment.
3. Variability of family income and family structure.
4. Variability of mothers' education which we cannot find in some Saudi cities.
5. Sociality of the population who live in this area which makes them more understanding and open-minded than many other Saudi cities.
6. The institutes in these cities contain children from all the surrounding cities and villages because these two cities have all the ID institutes and schools which can lead to variability of family background.

## 5.11. Conclusion:

The Saudi Arabian population is homogeneous and they share a number of common characteristics. For example, all Saudi citizens speak the same language, Arabic, and everybody believes in the same religion, Islam, and most have a tribal background (Al-Ghamdi, 1991). However, there are differences in language accent, and some social conventions.

About three decades ago, before the discovery of oil, Saudi Arabia was an isolated country educationally, politically, economically, and socially (Al-

Marsouqi, 1980). The development and modernization of the kingdom has increased dramatically during the last few decades as a result of producing and exporting oil (Bin Battal, 1998).

In spite of the huge revenues from the oil boom, Saudi Arabia has not lost many traditional and social values. Islamic law still governs all aspects of life, such as relationships, work, education, and so forth. As a result, changes in values have been decidedly tempered. In addition, the family seems not to be keeping pace with such progress and changes, and it tends to be conservative in its traditions, values, customs, attitudes, beliefs and behaviour. However, some important and dramatic changes have taken place, such as the progress in special education, general education, the health services, and some family characteristics such as polygamy and age at marriage.

Finally, by the year 2010 the Saudi population is expected to be about 30 million (see Appendix 10). In addition, by the year 2006, it is expected that the Saudi disabled population will be one million (Europa, 1997). To better serve this rapidly increasing population, more scientific study and careful planning for special education are needed.

# CHAPTER 6

# PLAN OF INVESTIGATION

## 6.1. Introduction:

The current chapter will give a brief outline of the methods and designs presented in the following chapters, which will provide detailed information about each study. The studies included in this thesis involve four samples. The first study dealt with mothers of children with intellectual disability (ID), the second with bilingual mothers and fathers, and the third with mothers of typically developing (TD) children and mothers of children with ID. Finally the fourth study tested the hypothesised model with mothers of children with ID.

## 6.2.Rationale:

Different stress and coping models of adjustment to disability have been discussed in Chapter two. One of the models, which has frequently been applied in studies of disabled children, is the transactional stress and coping model (Lazarus & Folkman, 1984). The associations between the variables in the model have been tested in many studies. Yet, as far as the researcher knows, neither this model, nor any other models have been tested with various kinds of population such as the Middle Eastern Arab and especially the Saudi population. In addition, none of the previous models have included family characteristics from a non-western point of view. For example, they have not tested the effect of polygamy, or family structure (i.e extended or nuclear) on mother's stress and mental health status, etc. Furthermore, most of the questionnaires on stress and coping have not been translated into Arabic and factor analysis with the Arabic and Saudi population have not been tested in the case of most, if not all, of the questionnaires.

To sum up, all of the scales of stress and coping have been produced from a purely western point of view. Hence, some of them need to be modified in order to be used with Middle Eastern Arabic societies such as Saudi society.

## 6.3. Main research questions:

1. To what extent are the study questionnaires applicable to the Saudi culture in the mothers' opinion? (Study 1)
2. What are the reliability and the validity of the translated and modified questionnaires? (Study 2)
3. Are there any differences in coping, stress, and maternal mental health (anxiety & depression) between mothers of TD and mothers of ID children? (Study 3)
4. What are the factor analysis differences between the Arabic translated scales compared to the original scales? (Study 3)
5. Does child IQ or BD predict maternal well-being (stress, anxiety and depression) after controlling for other factors? (Study 4)
6. Are the links between child disability and maternal well-being (stress, anxiety, and depression) mediated by coping strategies and social support? (study 4)
7. Are the links between child disability and maternal well-being moderated by coping strategies, social support and family structure? (Study 4)

These are the main research questions of the whole thesis and detailed questions about each study will be presented in the following chapters (see Figure 11, Chapter 4).

## 6.4. Methods:

### 6.4.1. Ethical Approval and consent:

Ethical approval for the four studies was obtained from the School of Psychology Ethical Committee, University of Southampton. Verbal and written consent was obtained from all participants. In addition, for the third and the fourth study the researcher has been given a written approval to work with mothers of TD and ID children by the Saudi Arabian Ministry of Education to enter the schools or institutions, and to see the students' files and so on.

### 6.4.2. Female researchers in Saudi Arabia:

There are many difficulties facing researchers in third world countries in general and in Saudi Arabia in particular. The lack of statistics and data is a major problem. It is difficult to find updated data because of a lack of research and where these data are available, they are usually unpublished and hard to find. Although both male and female researchers face many difficulties in Saudi Arabia, we are going to focus on the females' problem in this section because we believe that the female researcher faces more problems than the male and because the researcher in this study too is female.

The separation between males and females in every aspect of life is a major difficulty for the researcher. For example, female researchers are not allowed to enter boys' schools if they want to recruit students or teachers or even parents of male students. This can apply to the male researcher too, who cannot enter girls' school for the same reasons. If a female researcher needs to interview fathers or other adult males, she is not allowed to visit them at home or meet them in public or in schools, a telephone interview might be the safest way both for her and the participants. However, even with the telephone interview, she has to expect that there will be many conservative participants who will not even accept this. This situation can also apply to the male researcher too, when he wants to interview mothers or any adult female participants.

It is difficult for female researchers to visit ministries if they need something. She always needs a male mediator between her and these governmental offices. This does not apply to male researchers, who can enter any governmental offices or ministries.

In this study, the researcher faced some problems regarding male institutes. The governmental institutes are separated by gender, whereas the non-governmental institutes are mixed. However, only female teachers are employed in the non-governmental mixed institutes. This situation made it difficult for the researcher to enter the boys' institutes to view students' files, or to interview mothers, or to discuss many issues with the social workers. We tried to overcome this problem by contacting the male schools by telephone. The things needed from male social workers were discussed with them on the telephone. The questionnaires were sent to mothers by the social workers. The data needed from the children's files were gathered by the social workers as well. In the case of illiterate mothers, they were invited to the girls' institutes to meet the researcher or the social worker to help them to fill in the questionnaires. In addition, if the researcher needed to send or receive anything from a male institute, someone (male) from her side was sent to the schools to give them or receive from them any thing.

It is worth mentioning that in spite of these many difficulties, the researcher received great support from the ministries and from the schools and that this support might have reduced some of the difficulties.

### 6.4.3. Finding parents of children with ID:

The key question before collecting data was: Where can I recruit participants? And how can I recruit them? After researching, we concluded that there are five places to go to recruit participants for this study:

1. Governmental institutes for children with ID
2. Non-governmental institutes for children with ID
3. Paediatric clinics
4. Early intervention centres
5. Ministry of Social Affairs

When we recruited this study sample, only two resources from the list above were chosen: the governmental and the non-governmental institutes. The reasons not to use the other three was that the ministry of Labour and

Social Affairs family files are confidential and information about the families who receive benefits from the ministry may not be disclosed. Although there are early intervention centres in Saudi Arabia as far as the researcher knows, such centres are not available in Makkah and Jeddah and the non-governmental institutes are the ones who provide the early intervention services. Finally, the paediatric clinics option was ruled out because there are hundreds of private and governmental clinics in Makkah and Jeddah. In order to find adequate numbers of participants we would have needed to search most or all of these clinics in order to find which of them had intellectually disabled patients. This is because there are no statistics or data about clinics and each clinic holds its own data and files.

When we decided that we would recruit participants from governmental and non-governmental schools the Ministry of Special Education in Riyadh was contacted for permission to enter the schools, to meet children and mothers, meet the students, and receive help from counsellors or social workers. All documents needed for the study were sent to them, they contacted their male and female offices in Jeddah and Makkah. These offices were responsible for providing me with the help needed, and they contacted schools asking them to provide me with help for the study. They were very organised, very helpful at every stage from distributing questionnaires, interviewing mothers, provide help to illiterate mothers, to collecting and sending back the questionnaires. It is worth mentioning that without their help, it would have been impossible to collect data from boys' schools for the reasons mentioned in section 6.4.2 above. The questionnaires were returned without major delay because of the help of the social workers in these institutes.

## 6.4.4.Participants and Procedure:

### 6.4.4.1. Study 1:

In this study, twenty mothers of children with different IDs were interviewed in order to learn about their ideas and views relating to the questionnaires that were going to be used in the main study. (for more details of the samples, see Chapter 7).

The participants' responses to the questions asked in the interviews were submitted to textual analyses. Content analysis was used in all cases for analysing data because it allows one to deal objectively with meaning.

Content analysis is generally defined as a kind of analysis that reduces freely occurring text to a much smaller summary or representation of its meaning (Marshall, 1998). It is a research technique for the objective, systematic, and quantitive description of the manifest content of communication, which involves classifying contents in such a way as to bring out their basic structure (Abercrombie, Hill & Turner, 2000; Marshall, 1998). In general, content analysis is a systematic counting of the occurrence of ideas, themes, etc. in any body of verbal materials (Sutherland, 1995). It is primarily associated with written communication, but may be used with any form of message, such as television and radio, speeches, films, and interviews (Shaughnessy and Zechmeister, 1990). Thus, researchers who use content analysis create a set of categories which illuminate the issues under study and then classify content according to these predetermined categories (Abercrombie, Hill & Turner, 2000).

Accordingly, the researcher will follow Al-Awad's (1997) and Turner et al. (2004) strategies in this study and thus focus on themes as units of classification and will use two levels as follows.
Firstly: Recurring themes in the responses of each group to each question will be defined. Major themes will then be selected.

Secondly: The content's significance will be examined and the relationship between themes explored. Hence, the analyses will move from a descriptive to an explanatory and interpretative approach.

The aims of the text and preliminary themes were:

1. To characterise the text as accurately as possible.
2. To describe and differentiate the subtitles of themes.
3. To ensure that the questionnaires were appropriate to use in this culture and with this specific group.
4. To change or delete some inappropriate items from the original questionnaires which are not appropriate to Saudi cultures or to these mothers.
5. To add some items which are not mentioned in the questionnaires, but which mothers think are important.

With these five aims in mind, many areas were surveyed. These were: social support, family structures, stress, mental health, and coping strategies, in addition to their demographic data. (see Chapter 7).

#### 6.4.4.2. Study 2:

A translation process will be used in order to translate all of the original scales into Arabic. There are four basic translation methods more common than the others used in the literature: back translation, bilingual technique, committee approach, and pre-test procedure (pilot study). These methods can be used individually or can be combined to meet the requirements of a specific translation project (Brislin, 1980).

Before describing the translation process which was used in this study, a brief definition of each method is provided as follows:

**a. Back translation:** This technique involves two or more bilingual individuals. The first is asked to translate from the original to the target language, and then the other person is requested to translate the passage back from the target language to the original language. These two individuals should work independently. The back translation version is then compared with the original scale and any differences in meaning should be noted (Preito, 1992). This method is likely to provide a more accurately translated instrument than would be possible if one were relying on only one individual bilingual person (Prieto, 1992).

**b. Bilingual technique:** This technique involves bilinguals completing the instrument in both languages, or two bilingual groups taking different halves of the test in the two languages (Prieto, 1992).

**c. Committee approach:** This method refers to two or more bilingual individuals who translate from the original to the target language and then compare their translations (Brislin, 1980).

**D. Pre-test procedure (pilot study):** This method, which encompasses field-testing of the translation, is usually used after the translation is done. The translated material should be field tested to ensure the quality of the translation and also that participants can understand it (Brislin1980).

In translating this study's questionnaires, the researcher followed Vallerand's (1989) methodology in the cross-cultural psychology field. He suggested seven steps to follow for the translation and validation of an instrument.

1. Preparation of preliminary version.
2. Evaluation of preliminary version and preparation of an experimental version.
3. Pre-test of an experimental version
4. Evaluation of the content and concurrent validity
5. Reliability analyses
6. Evaluation of the construct validity
7. Establishing norms

Regarding this study, few procedures have been followed. After obtaining the authors' permission to use their instruments and translate them in to Arabic, firstly, the researcher translated the questionnaires into Arabic.

Then a person fluent in both languages performed the initial translation from the original language (English) to the target language (Arabic). The Arabic translation resulting from this first step was given to a bilingual psychologist. He back-translated the Arabic questionnaires to English. Then both versions were compared by the back-translator to check for mismatches between them.

The second step was the evaluation of a preliminary version and the preparation of an experimental version, using the committee approach. The research committee consisted of three psychology professors. The committee was provided with both the original and the Arabic versions resulting from the step above. After minor revisions had been made, an experimental version was produced.

The third step is the pre-test of the experimental version, which consisted of two main subordinate steps: *Field test or pilot testing;* here, a group of 25 mothers were recruited from special education and TD schools. A study was also conducted of bilingual participants (validity), in which thirty bilingual participants were recruited. (see Chapter 8).

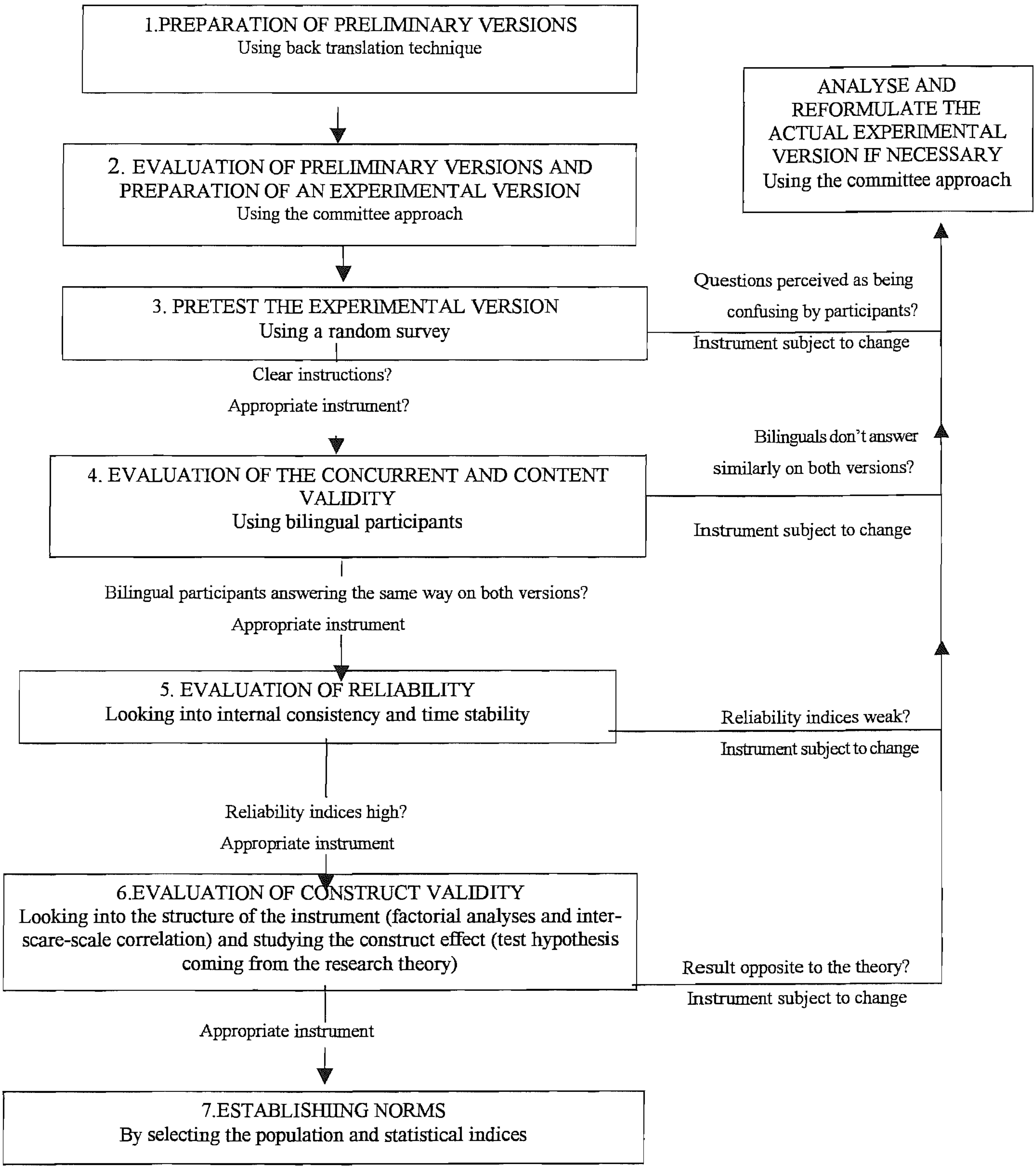
The fourth step was the evaluation of the concurrent and content validity. In content validity, the committee assessed the accuracy of the translated statements by measuring the concept associated with each statement. In the concurrent validity, we used a paired t-test (a non-significant “p” will indicate the similarities of the statements) and a Pearson correlation (a high correlation will indicate similarities of the statements)

In the fifth step, which involving the evaluation of reliability, we tested internal consistency and test-retest reliability using 25 mothers of TD children.
The sixth step, which was the evaluation of the construct validity, we found correlations between all English and Arabic scales (for more detailed information see Chapter 8)

Valerand's methodology has been used in many studies (Banvile et al., 2000). However, other studies found in the literature completed only some of the steps suggested. Banvile et al. (2000) reported that some studies omitted steps three to five, which are used to check for validity and reliability (Degrace & Pelletier, 1993, cited in Banville et al., 2000), while others (St-Laurent, 1990, cited in Banvile et al., 2000) did not use a bilingual group and did not test content and construct validity. Some studies (Brislin, 1986) used professional translators instead of using a back-translation technique as suggested by Vellerand. In other studies (Bin Batal, 1998; Prieto, 1992) only steps one to three were used. Figure (13) illustrates Valerand's process.

In this study, we believe that to make the research comparable with western studies, it is important to use existing well-established western measures. However, some measures have statements which are related to certain cultures that make it essential to delete or change these statements before we start the translation process. In addition sometimes the new culture into which we translate the measure, has specific belief or traditions which must be included in the original scale. Particularly, these measures may not contain all constructs relevant to mothers in Saudi Arabia. Therefore, additions to the questionnaire must be made. As a result, we recommend adding one more step to Vallerand's cross-cultural translation technique. It can be considered as a pre-translation step (pilot research). The reason we have added this further stage to the process to see if anything should be added to the measures before they are translated into the new language (see Chapter 7, Study 1).

Figure (13), Vallerand's cross-cultural translation techniques (Benville, et al, 2000)



Banville et al. (2000) insisted that the translation process should take place before any research is conducted using the instrument. Moreover, the translation process should be seen as a pilot study that will help determine whether or not the instrument is appropriate for the target population.

The PSI-SF was already translated into Arabic, although there was no published research in which it had been used with Arab population. Moreover, the reliability and the validity of the translated version had not been tested. Therefore, the Arabic PSI-SF was included in the testing procedure detailed below, while the HADS had already been translated and used with Arabic and Saudi samples, (El-Rufaie, & Absood, 1983; El-Rufaie, 1987) and it was included in steps 5, 6, and 7 to retest its reliability. The application of Valirand's methodology to the translation and testing of five instruments (Brief COPE, SPS, FSS, HADS and PSI-SF) is described in Chapter 8.

### 6.4.4.3. Study 3 (The main study, Introductory step):

Five hundreds and four (504) mothers of TD children and 513 mothers of ID children were recruited to this study in order to test the reliability and the validity of all the scales. In addition, the t-test has been used to test the differences between the means of the Arabic and the UK samples and it was used in order to find the differences in coping, social support, stress, anxiety and depression between Saudi mothers of children with and without ID. Furthermore, factor analysis has been tested for all scales (see Chapter 9).

### 6.4.4.4.Study 4 (The main study, testing the model):

This study may be considered as the main study with 513 participants of mothers with children with ID. A path model of mediations and moderations was tested with 513 mothers of children with ID. Regression analyses were used to test moderation and mediation. (see Chapter 10)

## 6.4.5. Measures:

### 6.4.5.1. The demographic data scale:

The demographic data were directly derived from the socio-economic scale (Abu-Ali, 1989) with the subtraction of some items and with some addition of items such as questions about type of family (extended or nuclear). In studies one to four, some questions about kind of disability and other disabilities in the child or other disability in the family were added. Whereas when it was used with TD population the items which indicated disability were omitted.

The new form of the scale was submitted to two psychology professors in the University of Umm Al-Qura in Makkah, Saudi Arabia to ensure that all the new items and the changes were appropriate for use with the study sample. The scale consisted of parental age, education, occupation, child age, school, level of education, family income, family structure, number of children, polygamy, and housing. (see Appendix 2 for more details how this scale was used in all the following four studies.

### 6.4.5.2. Hospital Anxiety and Depression Scale (HADS): (Zigmond, and Snaith, 1983). Translated by El-Rufaie (1987):

The HADS is a four-point rating scale consisting of fourteen items. It provides separate measures of two constructs, anxiety and depression: seven items for anxiety and seven for depression. The two sub-scales can also be aggregated to provide an overall anxiety and depression score. The overall results for the scale are categorized as (0-7 Normal, 8-10 Mild, 11-14 Moderate, and 15-21 Severe), above 10 indicates a probable disorder of the relevant mood (Zigmond & Snaith, 1983). The participant is instructed to complete the scale in order to reflect the present state i.e. over the past days or so. It has enabled researchers to establish the presence and severity of both anxiety and depression simultaneously, while giving a separate score for each. It gives a cut-off-point to indicate when someone is within the normal range, or in a mildly, moderately, or severely disordered state. The scale has been translated into all major European languages. Moreover, other translations include Arabic, Hebrew, Chinese, Japanese, and Urdu. This measure has been used in Chapters 7, 8, 9 and 10. Because this scale has already been translated to Arabic and has been used with a Saudi sample (El-Rufaie, 1987), it was not included in the initial translation process. However, only its test-retest reliability was tested in Study 2 (Chapter 8).

#### 6.4.5.3. The Parenting Stress Index Short Form (PSI-SF), (Abidin,1995):

This scale has been included in all of the following studies, Chapters 7, 8, 9, and 10. The PSI-SF is a short form of the original Parenting Stress Index (PSI) (Abidin, 1993). It consists of 36 items, which are answered on a 5-point scale (1= strongly disagree, to 5= strongly agree).

The PSI-SF was developed following the factor-analytic studies of the PSI (Abidin, 1993), which identified three factors: (1) parental distress (PD), which include items relating to role restriction, isolation, depression, spouse, competence and health (e.g. "I feel trapped by my responsibilities as a parent"); (2) parent-child dysfunctional interaction (P-CDI), which includes items relating to attachment, competence, reinforcing parents, acceptability (e.g. "my child is not able to do as much as I expected"), mood and adaptability; and (3) difficult child (DC), which includes items relating to adaptability, demandingness, mood (e.g. "my child generally wakes up in a bad mood") and acceptability. Each of these three subscales comprises 12 items. The sum of these three dimensions together gives the total score of parental total stress. In general, the normal range of scores is 15 to 80. A high score is considered to be above 85. Parents who obtain a total score above a raw score of 90 are experiencing clinically significant levels of stress and thy should be referred for closer diagnostic study and for professional assistance (Abidin, 1995). It must be remembered that the total stress scale score does not include stresses associated with other life roles and life events. Thus, this should never be interpreted as anything more than an indication of the stress level experienced within the role of parent (Abidin, 1995).

#### 6.4.5.4. The Brief COPE (Carver, 1997):

This is a 4-point scale from 1 (I did not do this at all) to 4 (I did this a lot). This scale has been used with all of the following studies, Chapters 7,8,9 and 10. This scale reports a brief measure of coping, based on a coping inventory (Carver et al., 1989) but the Brief COPE omits one scale of the full Cope, and reduces the subscales' items to two instead of four. It includes only 28 items which measure 14 conceptually differentiable coping reactions: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self blame. Each one of these fourteen subscales comprises two items. In the original COPE scales each subscale had four items (Carver et al., 1993).

#### 6.4.5.5. Social Provision Scale (SPS) (Cutrona and Russell, 1987):

This scale has been used with all of the following studies, Chapters 7, 8, 9, and 10. This scale is an alternative to the original version of the SPS (1978). It is a four-point scale (from strongly disagree to strongly agree). The scale comprises 24 items, and contains six dimensions: Guidance, Reassurance of Worth, Social Integration, Attachment, Nurturance, and Reliable Alliance. Each subscale includes four items (with two positive and two negative items). This scale has been used in a wide range of participants from community samples such as school teachers, nurses, students, mothers, and with the elderly (Cutrona & Russell, 1987)

#### 6.4.5.6. The Family Support Scale (FSS) (Dunset, Jenkins, and Trivette, 1993):

This scale has been used with all of the following studies, Chapters 7, 8, 9 and 10. The FSS is a multi-dimensional assessment tool. It is designed to measure the degree to which different sources of support help families rearing a young child. This is a five-point rating scale from 'not at all helpful' to 'extremely helpful' consisting of 18 different sources of support. The sources of support can be considered as five sub-scales: partner/spouse, informal kinship, formal kinship, social organizations and professional services. This tool can be used in both clinical and research settings to access a range of information about family social networks. (Dunset, Jenkins, and Trivette, 1993). McDowell et al. (Dunset, Jenkins, and Trivette, 1993) found the FSS to be sensitive to differences in ethnicity, with declines in family resources and social support being predictive of increased parenting stress in white families of medically fragile children, but not in similar non-white families participating in early intervention programmes.

In addition to the helpfulness of social support, the FSS can also measure the number of sources of support (network size) by decoding participants' answers. Items rated "not available" must be given a score of 0. Whereas, all ratings of helpfulness (from 1 to 5) must be given a score of 1. These can be summarized to give totals for each separate types of support as well as for overall source of support.

### 6.4.5.7.The Strength and Difficulties Questionnaire-Parent report (SDQ) (Goodman, 1997):

The SDQ is a brief questionnaire that can be administered to the parents and teachers of 4-to 16-year-olds and to 11-to 16-year-olds themselves (Goodman, 1997, 1999, 2000, Goodman et al, 1998). It contains 25-items that cover common areas of emotional and behavioural difficulties (Goodman, 2000). The 25 items generate 5 subscales: Conduct problems, hyperactivity, emotional symptoms, peer problems, and prosocial behaviours (see Appendix 9 for list of items). Each item has three possible answers (not true, somewhat true and certainly true). A total behaviour difficulties score can be found by summing the first four subscale scores producing a total score 0 to 40 (Goodman, 1997). Higher scores on the prosocial behaviour subscale reflect strengths, whereas higher scores on the other four subscales reflect difficulties.

This questionnaire has been translated into over 40 languages (Goodman, 2000) and its reliability and validity were examined and were found to be generally satisfactory when used with many samples from different cultures such as a British sample (McMunn et al, 2001; Glazebrook, et al., 2002), Swedish (Smedje et al, 1999), German (Klasen et al., 2000), Dutch, (Muris, Meesters & Van den Berg, 2003; Widenfield et al., 1999), Yemeni (Almaqrami, & Shuwail, 2003) and Bangladeshi (Goodman, Reffrew, & Mullick, 2000; Mullick & Goodman, 2001).

The SDQ has been translated into Arabic by Thabet (1998) who has used it with a sample of 322 parents of children from a general population in the Gaza strip, Palestine in order to test its factor structure (Thabet, Satretch & Vostanis, 2000). In addition, the self report version was used with 600 participants from a community sample in Yemen (Almaqrami & Shuwail, 2004) the alpha level for the total score and subscales were ranged from .77 to .89.

In general, the SDQ is a well validated instrument and has been proven to be as effective as both the Child Behaviour Checklist (Achenbach, 1991) and the Rutter scale (Elander & Rutter, 1996) in identifying clinically significant levels of behavioural disturbance in children (Goodman, 1997; Goodman & Scott, 1999).

Internal consistency (Cronbach's alpha) was found to be above .80 for the total difficulty scores (Goodman, 2001) and it was .80 in another study (Muris et al., 2003). On the other hand, Emerson (2002) reported internal consistency data for mothers of intellectually disabled children of .71 for total difficulties. For subscales Cronbach's alpha was reported in many studies (e.g Muris et al, 2003; Smedje et al., 1999) for prosocial behaviour (.62/.70), hyperactivity (.78/ .75), emotional symptoms ( .70/ .61), conduct problems (.55/ .54), and the peer problem subscale (.66/.55). A test retest reliability of .85 has been reported for the SDQ total score (Goodman, 1999) and it was in the .70 range or higher for the scale or subscales (Murris et al., 2003). This scale was not included in the translation process chapters (7 and 8) and it has only been used in study 3 and 4 (Chapters 9 and 10) only with mothers of intellectually disabled children.

### 6.4.4.Definition of terms:

**6.4.4.1.Stress:** Lazarus and Folkman (1984) defined stress as a condition in which an event is appraised as taxing or exceeding individual resources, emphasizing the importance of the balance between the demands placed on a living system, and its adaptive capacity to cope with its burden. Whereas, Abidin (1995) defined stress as the imposition of strain on a person or the effects of the strain on him/her. Prolonged stress may impair functioning or trigger mental illness. It is operationally defined in this study as the total score of the PSI-SF.

**6.4.4.2.Mental health:** Attitude toward the self; growth, development, and self actualisation; integration; autonomy; undistorted perception of reality; and environmental mastery (Sills, 1982). It is operationally defined in this study as the total score on the HADS (anxiety and depression) (Zigmond & Snaith, 1983).

**6.4.4.3. Intellectual Disability (ID)**: Intellectual disability defined by AAMR as low general intellectual functioning as measured by IQ scores, significant impairment in adaptive behaviour and conditions manifesting before age 18. Intellectual disability is viewed as the most appropriate term to replace the previously defined terms of developmental disability or mental retardation. According to this study Intellectual disability was measured by child's IQ, and Behavioural Disorders (BD).

***a. IQ***: The possession of an IQ below 70 indicated disability, manifesting itself before adulthood, they divided into mild (55-69), moderate (40-54), severe (25-39), and profound (below 25). (Southerland, 1995). In this study only mild and moderate disability will be included by using Stanford-Binet test.

***b.* Behaviour Disorders (BD):** In general, BD can be defined as any maladaptive habit not caused by genetic damage or directly related to psychosis or neurosis, especially in children or young people (Sutherland, 1995). However, in this study we will focus on Goodman's (1997) definition of behaviour disorders as the total score on the child's emotional symptoms, conduct problems, hyperactivity, inattention and peer relationship problems. A total score of the first four subscales of the Strength and Difficulties Questionnaire for completion by parents (SDQ) (Goodman, 1997) will represent the child behavioural disorders in this study.

**6.4.4.4. Family structure:** which is in the present study divided in to: (a) extended family: the families which consist of three or more generations who usually live close together and engage in common activities. (b) nuclear family: a family that consists of only the parents and their children, (El Ashwal, 1987).

It is worth mentioning here that because there is no independent scale to test family structure, we have added four questions about family structure in to the demographic data scale (see Appendix 2). These questions ask who lives with the family in the same house and how faraway do the grandparents live, How frequently does the family visit their grandparents?

**6.4.4.5. Coping:** Lazarus and Folkman (1984) defined coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taking or exceeding the recourses of the person. On the other hand, Sutherland (1995) defined coping as any behaviour whether deliberate or not, that reduces stress or enables a person to deal with a situation without excessive stress. According to this study coping is operationally defined as the total scores of the Brief COPE Scale (Carver, 1997).

**6.4.4.6. Social support:** This is actual or perceived availability of resources in one's social environment that can be used for comfort or aid, particularly in times of distress (Ramachandran, 1994). The total scores on the FSS (Dunst, Trivette & Hamby, 1993) and the SPS (Cutrona, 1984) have been defined as the resource of social support resources in this study.

It is worth mentioning that unlike other measures, two scales have been used in order to test social support. Because three categories of social support were tested: satisfaction with support by using SPS, number of source of support (network size), and level of helpfulness of social support by using the FSS.

## 6.6. Conclusion and Plan of the research:

In the next few chapters, several studies will be discussed. Each chapter will outline the specific participants' characteristics and measures that have been used for the purpose of the described study. Chapter 7 describes the exploratory study with mothers of disabled children. Chapter 8 is the translation process study of all the questionnaires. Chapter 9 is the normative and the disabled sample study, which includes a large number of mothers of TD and ID participants in order to find norms from all the questionnaires and to test the new factors of the translated scales. Chapter 10 is the fourth and main study, which included parents of children with ID in order to test the study model. And finally, Chapter 11 is the conclusion and the results established from the whole study.

# CHAPTER 7

# EXPLORATORY STUDY (STUDY 1)

## 7.1. Introduction:

Theorists have examined some of the ways in which socio-historical contexts influence the formulation of issues in developmental psychology. They assessed how important it is to examine the social, political, religious, and historical forces of culture when trying to understand the discipline (Stratton, 1990; Wertsch & Youniss, 1988).

In Chapters 4 and 5, we showed that the Saudi culture and lifestyle is different from western culture. It is therefore likely that mother's judgements about themselves, their families, their children, stress resources, and their ways of coping will be different from those in western cultures. Religion and customs are likely to affect their views. Conceptions are likely to be bounded by worldviews held in different cultures, their goals and ideas (Al-Awad, 1997). This means certain coping strategies or behaviour that are acceptable in one culture will be unacceptable in another. This may mean that sources of stress that are deemed not to be serious in one culture will be positively harmful to the mothers in another culture; likewise, coping strategies that are employed in two cultures may be more effective in one than in another.

These differences stress the need to provide the non-Saudi or the British reader with an opportunity to familiarise themselves with the sort of views held by the Saudi mothers about themselves, their families, the stresses they faced, and their ways of coping. In addition, it is very important to check for concepts that might need to be added to the measures to be translated.

## 7.2. The aim of the study:

1. This study is the first of its type in Saudi Arabia to focus on mothers of intellectually disabled children and will lead to a better understanding of differences between Saudi and western culture.
2. The study aims to chose and design the ideal questionnaires for use in the main study.
3. The study provides information which helps the researcher to tailor the questionnaires to Saudi mothers.

## 7.3. Purpose of the study:

The thesis in general will focus on the fact that the universalist position has been challenged by determining standards of normality and abnormality (Reid, 1995) by shaping personality in the context of specific environmental demands (Marsella & Schever, 1987).

There have been no studies of family stress, coping, social support and mental health in Saudi Arabia. The main purpose of this study was therefore to develop an understanding of Saudi mothers' attitudes to their disabled children, their families, their ways of coping, what are the stress factors that they face, and their most supportive resources. In other words, the interview investigated the role of religion and culture in formulating ideas about the study variables. A more important purpose of the study was to check for concepts that might need to be added to the measures to be translated or to be changed.

## 7.4. Methods:

### 7.4.1. Participants:

Twenty mothers of ID children were recruited whose mean age was 37.6 (SD=6.43). Eighty five percent of them were married and 15% widowed. Their mean number of years of education was 12.2 (SD=4.78). Seventy five per cent of the participants were housewives and 25% were working women. The mean number of children per family was 4.35 (SD=2.00). The mean age of the children was 7.9 (SD=2.70). Seventy percent of the children were male and 30% female.

The kinds of disability were as follows: 45% Down's Syndrome, 25% autism, 10% cerebral palsy, 10% fragile X syndrome, 10% moderate disability with unknown aetiology.

### 7.4.2. Sample selection and recruitment:

Mothers of children with an ID were asked by telephone for their permission to include them in this study. A brief description of the study was given to them, and they were told how long the interview would be. Twenty mothers agreed to take part. In the interviews, the researcher introduced herself to the mothers, then gave participants a consent form and a debriefing statement about the study which included the information sheets explained the project, that the information from interviews would be kept confidential and that mothers were free to withdraw from taking part any time they want without it affecting the services they received from children's schools. In addition, they were also informed verbally that they could withdraw their consent at any time.

Before starting the interview, participants completed a demographic questionnaire giving information about the child, the mother, and the family (see Appendix 2). The researcher also asked the school doctor about the kind of disability the children had in order to confirm the information provided by the mothers. The interview did not take more than 35-45 minutes with each participant. After finishing, the interviewer thanked the participants and asked them if they would like to receive the results of the study at a later date.

### 7.4.3.The interview schedule:

The interview was semi-structured and consisted of five sections. In brief, section one inquired which family structure and which kind of family (nuclear or extended) the mothers thought best in Saudi culture and why. Section two investigated ideas about coping strategies used by the mothers and which was the best. Section three was concerned with social support and discovering who was the most supportive person for the mothers, while the fourth section inquired about stress and stressful situations for mothers. The last section was about the mothers' mental health and to what extent they felt anxious or depressed (see Appendix 1 for more detail).

### 7.4.4. Data analysis:

The participants' responses were submitted to content analysis. Content analysis was used because it allows the meanings to be dealt with objectively. It is important to mention here that a full analysis is not done here. It is exploratory study that was designed to inform the next stage of the research. So, a qualitative approach, with thematic analyses was used.

## 7.5. Results:

The mothers were interviewed separately. Their views about themselves, their children, spouses and families will be compared in this section.

### 7.5.1. Family structure:

#### 7.5.1.1.Mothers were asked which family structure they think is the best in their society and why

Twelve mothers (60%) thought that the best family structure in Saudi Arabia is the extended family. Two of them agreed that it is better to live in an extended family but they did not think that it was a good idea to share the same house. They thought that living in the same compound or building with the family is the best.

> "The extended family is better in our society, because we are usually depend on each other in case of emergency and in daily life. But it is not a very good idea to live in the same house, especially with your parents-in-law, because the grandmother will be responsible for decisions in the house. Usually this does not suit the mother, which will give rise to problems. In my view the best form is the extended family living in the same building or compound. This makes everyone responsible for his/her own house and at the same time they have the support of their family". D

One participant (5%) whose husband has a physical disability and three (15%) of the widowed mothers agreed that the extended family is very important to them.

" It is impossible to live on your own if you are single mother (widowed or divorced), especially if you have children with special needs. Living with the extended family either in the same house or in separate houses in the same compound will provide support to the mother and the child too". P

" Although we don't live with our families, I think that living in an extended family is better because women are not completely independent in our society. Moreover, if you have a child with special needs and a disabled father, you always need help from others, even your own family or your husband's family". F

Two mothers now living in a nuclear family who used to live with their parents-in-law thought that there family structure was better before.

"Without doubt, the extended family is much better in our society, especially if there is a child with special needs in the family. I felt better when we lived with my parents-in-law. At least I felt comfortable when I went out, especially at night". A

Four mothers (20%) agreed that the extended family sometimes causes slight problems among its members, especially the mother and the mother-in-law. However, they thought it better than living in a nuclear family.

"I think that the extended family forms a better structure in our society, in spite of slight problems which sometimes happen between the mother and her mother-in-law when they share the same house. However, grandparents usually play the role of the counsellor in the family. Children sometimes accept their grandparents' commands about specific things more than their parents'. When the parent wants to go out for a long time, grandparents are always the best child-minders. That makes parents feel at ease to go and enjoy themselves". H

Only one (5%) mother thought that it was better for the parents if they decided to live in an extended family to choose the people who are going to share their life with them.

" In my opinion the extended family is better in our society for many reasons. However, it is not necessary to live with your parents-in-law if you don't like it. Parents should discuss which family is going to share their life. Because we live in a different city from my parents and parents-in-law, my husband and I choose to live with his sister's family in the same compound but different villas. I think this makes me feel more comfortable, especially when I need to go out and leave my children at home". M

On the other hand, eight mothers (40%) thought that the nuclear family is better for the independence of the family and the mother. Some of them thought that today's parents are more independent than in the past, so they do not like their parents or parents-in-law to interfere in their personal life.

"The nuclear family is better these days, because always in our society the extended family means that you have to live with your husband's family, not your own. Hence, most of the time this kind of family faces lots of problems between the mother and her mother-in-law which has a bad effect on the children and the husband too. I believe that today's mothers are more independent, they don't want to share the decisions about how to raise their children with anyone". O

Another mother added:

" Life has changed. It is becoming more complicated. So, the family in Saudi Arabia has changed too. It is difficult nowadays to live with your husband's family (because, as you know, this is the common extended family form in Saudi society) without any problems. These problems are the result of two or three authorities in the house. This may confuse the children about whom should they listen to, especially if the mother and the grandmother have different views". T

Two mothers (10%) thought that the nuclear form is better for children. They thought that the children were confused by the multiplicity of authority figures in the extended family.

"In my view the nuclear family is much better. My father-in-law has carte blanche. He chose our children's school, where to go on summer vacation, when to invite friends, etc. Of course, according to our tradition, my husband should follow his orders. This makes our children think in a different way about their father. They feel that their grandfather is more important and more independent. My husband and I always argue because of this situation. All of these problems happened while we lived in a separate apartment but in the same building. Imagine if we lived in the same house!".

" Living in a nuclear family does not mean that these parents deal impiously with their families, as some people think. In my view living in a nuclear family with weekly visits to the grandparents is better for all the family members and especially children. However, this doesn't mean that the extended family is not important in some cases, such as for single mothers (divorced, widowed), or in the case of very early marriage, which always happens in rural places". R

### 7.5.1.2. Do grandparents play a positive role in raising the child?

Seven mothers (35%) answered that their parents-in-law played a positive role in raising their children. Six of them lived in extended families and only one lived in a nuclear family. One of these mothers' remarked:

"My parents-in-law are very supportive to me and they play a positive role in raising my children, especially this child. I think if we lived in separate houses my situation would be harder, because I would be the responsible for everything and this might be a burden to me". H

Two mothers (10%) believed that their families played a positive role in their coping but not in raising their children.

" Because I live in a nuclear family I think neither my family nor my parents-in-law play any role in raising this child, whereas they play a very effective role in my coping. Both families are very supportive to me and to my husband".

Five mothers (25%) did not think that their families or families-in-law played any role either in raising their children or in their coping. Four of them lived in extended families whereas only one lived in a nuclear family.

" My husband's family doesn't play any positive role in raising my child, nor in my coping. On the contrary, my mother-in-law is a very critical person. She doesn't like my way of raising my children and especially this child. She believes that my child has a disability because of my carelessness. This disappoints me when we visit her". C

All the other cases that said that their extended families do not play any positive role, believed this happened because they lived far from them and do not see them often.

" I believe that my family and my husband's family don't play any role either in raising my child, or in my coping, because we live in another city, so we just see them once every two weeks or so". J

On the other hand, eight mothers (40%) thought that their extended families, especially their own mothers, played a positive role in their coping and in raising their children. One of the mothers who lived in an extended family remarked that:

"Although I live with my husband's family in the same building, my mother and sisters play a very effective role in raising my child and in my coping, because I think my husband's family is one of my problems. They are one of the reasons for my maladaptation to my situation" .Q

Other mothers said that they viewed their families as more supportive than their families-in-law did not mean that they had a bad relationship with their families-in-law.

"Even though I live with my parents-in-law, I believe that my own family, especially my mother, plays a very positive role in my coping and in raising my child. However, this doesn't mean that I don't like my parents-in-law or that I have a bad relationship with them. In my opinion no one can take the mother's place, even if you feel very comfortable with that person, you still feel that you can't express yourself as you can with your own mother".

Another mother said:

"My parents have grown very old, so they don't play a big role in raising my child. However, because they are very religious, they play very effective roles in making me feel better and able to cope with my situation. They teach me how to be calm and resigned". E

### 7.5.2. Mothers' coping:

The second section of the interview was about coping: mothers were asked fourteen questions related to their coping strategies. Questions were asked as follows.

#### 7.5.2.1. Have you tried doing things like watching television, visiting friends, shopping, etc to take your mind off things?

Eighteen mothers (90%) agreed that they usually do things that take their mind off things. Almost all of them chose television, talking on the telephone, visiting relatives and shopping as the most preferable activities for them. Three mothers (15%) preferred to do things other than social activities, i.e. things they can do at home.

" I prefer not to go out a lot, so I usually contact family and friends by phone. I also like watching TV, listening to FM and things like that, which do not involve going out". C

Two (10%) mothers responded that they hardly do anything other than looking after their children and their houses.

"Sometimes I feel that I am working like a machine, I do everything for my children and my husband (because of his disability). I feel that this doubles my responsibility compared with any other mother". L

Another mother added:

"I rarely do things which take my mind off things. For example, if I watch TV at night when every one is asleep, I can't enjoy it that much because I have to break off every few minutes to check that everything is O.K in the other rooms, especially if I hear a voice from my child's room. I am worried all the time that my child will have an epileptic fit while I am watching T.V". A

#### 7.5.2.2. Have you tried to concentrate your efforts on doing something about your situation?

All the mothers except one (95%) thought that they tried their best to improve their situation.

"I try my best to make my child more independent, so I spend more time with him in order to teach him new things, especially things that are needed for social life" R.

"I try to attend any workshops or lectures on special education in order to learn the best way to raise my child. Moreover, I usually read books about mentally disabled children and their families in order to understand it more" .B

Only one mother felt that she did not try to do things about her situation. She thought that God will take responsibility for changing it.

"Sometimes I try to do something about this situation to make it better. However, I believe that, even if I don't do these things, God would change our situation if he wanted to, without my help". P

#### 7.5.2.3. Do you believe that this thing has happened (your child's disability) or do you still refuse to believe it?

Two mothers (10%) did not believe what had been said to them by professionals about their child's ID to be true. They tried to cope with it by using wishful thinking.

" I don't believe that this is the end. I am a religious person and I am sure that God will change my child's case in the future, but we should be patient". I

One mother believed that her child was different and needed special care. However she believed that this would change in the future.

"I believe that my child is mentally disabled. However, I don't believe that this is it. I believe in God, and I know that he will find a solution to my case, such as the discovery of a new medicine that can make my child normal, such as cloning cells, which can be injected into the brain or things like that. I believe that this may happen in the near future". R

Four (20%) mothers accepted the situation and lived with it, but they thought that this acceptance came a bit late.

"Now I accept the fact that my child is intellectually disabled, but I think it has come a bit late because until a short time ago, I did not want to believe it. I refused to let him go to special school. I just waited for a miracle. Finally, I accepted that I can't go on denying it and I have to start to deal with it, because denial will not change it". N

All the remaining mothers (13 mothers, 65%) perceived that acceptance in term of religion.

" This is God's will. You don't have to like it, but you should accept it" P.

" I completely accept it. This is the will of God. I know that I have to work hard with my child instead of daydreaming and waiting for a miracle" .T

### 7.5.2.4. Do you use any kind of drugs or medicine to make you feel better?

Thirteen (65%) of them said that they did not use any kind of drugs, tranquillisers, or sleeping pills, and they would prefer not to use them, even if they needed them.

"Sometimes when I feel stressed, I think that I need to take some medicine, such as a tranquilliser to make me feel calm, but, I prefer not to use drugs at all, because I believe that if I use them once I will become dependent on them to make me feel better, and I don't like that"

Seven mothers (35%) said that they use drugs; five of them tranquillisers; one sleeping pills; and one both.

"I used tranquillisers and sleeping pills especially after the death of my husband. I felt that I was the responsible for everything. I couldn't sleep without sleeping pills, but now, I rarely use sleeping pills, but I use tranquillisers sometimes" I.

### 7.5.2.5.Have you been able to deal with the situation or not?

All of the mothers are still trying to deal with their situation. One of them commented:

"I am still trying to cope with it. The worst thing facing me is the curiosity of others about my child's case. This bothers me a lot, but I try to cope as much as I can with their curiosity ". J

### 7.5.2.6.Have you expressed your negative feelings to others?

All the mothers expressed their negative feelings to someone else, or to more than one person. Twelve (60%) of these mothers reported sharing their negative feelings with their husbands, eight (40%) had mentioned their negative feelings to their mothers, eight (40%) had mentioned it to their sisters or brothers, one (5%) mentioned it to her sister-in-law, one (5%) to her brother-in-law, three (15%) to their elder infants, and finally one (5%) shares her feelings with her best friend.

"Usually I express my feelings to my husband, although I try not to speak to him about my negative feelings, because he began to take it as a criticism of him, so usually it ends with arguing". C

" I always like to speak to my sister by phone because she lives in another city. I speak to her about my negative feelings and about my stress. Although I am sure that she doesn't have a solution to my problems, I like to phone her because I feel better after talking to her". N

### 7.5.2.7. Have you tried to see your situation in a different light in order to make it seem better or positive?

Seven mothers (35%) did not think that their cases could be viewed in a better or more positive way.

"I don't think this has any positive aspect. You can't imagine how the birth of this child affected my whole life". C

Thirteen mothers (65%) felt that they could see it in a different light to make it seem better. Three of the thirteen were concentrating on a religious point of view.

" I always say to myself that God has chosen me to be the mother of this child for a reason that we don't see, and I am sure that he will recompense her father and me if we are patient and try to do our best for her. Moreover, sometimes when I feel sorry about my daughter, I say to myself that she is better than us because her reward from God will be in heaven". A

"I thank God all the time for my children. I do have one disabled child, but he recompensed me with four normal children. Moreover, he provided me with good health and the faith to take care of my family". F

By contrast, five out of the thirteen saw their strong family relationship as positive for them.

"I usually feel lucky because I have such a family. I see my family, my husband's family and of course my husband as a positive light. I always thank God for surrounding me with these people". L

Two of the thirteen mothers who saw it in a different light had a different point of view. They focused their positive feelings on their economic position.

"I thank God most of the time for our economic status. I have a nanny, my child goes to a private school, gets treatment in a private hospital, etc. This makes me feel better because I think my situation is much better than that of other mothers". O

### 7.5.2.8.Do you have future plans?

Although all of them said that they worried about the future, and think about it, only five (25%) of them tried to plan for it. Four of these mothers, who thought that they were planning for the future, said that the only thing that they actually do about the future is to provide their children with a good economic status.

"His father and I opened a bank account for him. We try to support him economically as much as we can, because we don't want him to be dependent on anybody else if we die". E

One of these mothers said that her plan with her son for the future is to share the responsibility for his sister:

"I tried my best to teach my child to be as independent as she can. Moreover, I try to involve her brother in everything related to his sister, to engage him in this, because he knows that he will be responsible for her if something happened to me or to her father". N

Fifteen mothers (75%) said that they were very worried about their children's future and they did not know what to do about it. Most of them reported worrying when they think they may one day not be there for their child. Thinking about death causes the most anxiety about the future.

"The future is the only thing that depresses me when I try to think about it and when I try to plan for it, I fail. Because I can't imagine what will happen to my child if I die, I try to teach my other children not to forget their duty to their sister". G

### 7.5.2.9.Have you ever made jokes or fun of your situation?

Only three (15%) mothers said that they sometimes laugh at or make fun of specific things that have happened to them.

"Sometimes my children make jokes and laugh about a specific situation that has happened between me and their sister. Although I shouldn't laugh about it, I can't stop myself, especially if they start to imitate me". D

"When I try to teach my child something, it takes me a long time to do it. Sometimes during training, I start to get nervous of his reaction. Then, suddenly I stop and start to laugh about his reaction". B

Seventeen (85%) mothers reported never laughing at their situation.

"I get angry with my children or my husband sometimes when they make fun of our situation, because I feel that we shouldn't laugh about it". E

### 7.5.2.10.Do you blame yourself for things that have happened?

Four mothers said that they usually blame themselves, because in the past they refused to believe that their children were ID. Consequently, they refused any intervention until recently.

"Usually I blame myself for refusing to let my child go to a special school. I was just waiting for a miracle to happen. I feel that maybe I am one of the reasons that my child isn't developing very well, because he started school very late, when he was eight and a half years old". T

Nine mothers reported that this is their destiny, but they can't stop blaming themselves for things that have happened.

"Sometimes I blame myself for things that have happened. Although I am sure that these are out of my hands, I can't stop blaming myself". C

Seven mothers (35%) reported that they seldom blame themselves.

" I seldom blame myself for what has happened and, when I have, it has been because somebody blamed me". J

"I blame myself very rarely, especially because I am a religious woman and I believe in destiny". L

### 7.5.2.11.What are the effects of religion on your feelings?

All the mothers said that religion was an important part of their coping. Reading the holy Qur'an, visiting the holy mosque and praying are the most important religious coping strategies.

"Before having this child, I was not so religious. I felt angry, panicky and usually blamed myself for everything, but now I feel that I have a strong relationship with God. This makes me calm and a believer"
"Religious practice such as reading the Qur'an and praying have magical effects on me. It is the best thing for the soul. I believe there can be nothing better than communing with God". N

### 7.5.2.12.What do you think is the best way to improve coping?

Eighteen (90%) mothers mentioned religion as the best strategy for coping. Nine of these eighteen also mentioned family support as an important coping strategy.

"Believe in God and religious practices such as praying and reading the Qur'an are very important in making anyone feel better. Moreover, finding a trusted person to speak to is very important too". I

Four (20%) of these mothers who believe that religion is a very important strategy for coping better added that working hard with their children to teach them new techniques will also have a positive effect.

"The most important thing for coping better is acceptance and belief in our destiny. Beyond that we have to work hard to alter our situation, because I think when you see your child's progress it has a good effect on the parents". L

Only two mothers (10%) did not mention religion in answering this question. They focused on family support and acceptance.

"Strong family relationships are the best coping strategy, because if you try your best without help from the family, I think this will not give good results". K

### 7.5.3. Social support:

This section contains four questions that focused on the mothers' social support.

#### 7.5.3.1. Have you received support, comfort and understanding from anyone?

All the mothers reported that they had received emotional support from someone. Eight (40%) of them mentioned their husbands as one of the most supportive people. Seventeen (85%) mentioned other family members (4 parents, 7 siblings, and 6 mothers). Seven (35%) mentioned their families-in-law (4 parents-in-law, 1 father-in-law, 1 brother-in- law, 1 sister-in-law). Finally, only two (10%) mothers mentioned their best friends as the most supportive person.

#### 7.5.3.2. Have you received any formal support, and who are the people who are supportive in this way?

Answers to this question were not very different from those to the previous one. However, six mothers (30%) mentioned their children's doctors, their family doctors, counsellors, workshops that take place in the children's schools and their children's teachers as sources of technical support.

#### 7.5.3.3. Who are the other people who share your social activities and interests?

All the mothers agreed that there are people who share their concerns with them. They mentioned their family members, husbands and friends, but only four (20%) of them believed that they shared their concerns but not their interests and social activities.

"As I said before, my brother-in-law and my best friend are the most supportive people for me, so I believe that these two share my concerns. However, I don't think they enjoy the same interests and social activities as I do". B

#### 7.5.3.4. Do you have any emotional bond that provides you with a sense of emotional security?

Thirteen mothers (65%) mentioned their husbands as the person with whom they have a strong emotional bond.

"Although my husband and I usually argue because of this child, and we thought seriously about divorce a few years ago, I feel that our relationship has become stronger now than ever. I think he is the person whom I have a close emotional bond with" O.

Eight (40%) of them mentioned their families.

"I feel a very close emotional bond with my parents. I feel that I am part of them and very secure with them". I

Only three mothers (15%) mentioned an emotional bond with their husband's family.

"I feel very close to my husband's family whom we live with, specially with my father-in-law. Sometimes I feel that he is closer to me than my own father". L

Two mothers (10%) mentioned their best friends in this regard.

"My husband and my best friend are the people with whom I have a very close relationship and emotional bond" .B

### 7.5.4. Stress:

The third part of the interviews contained five questions about stress as follows.

#### 7.5.4.1. What are the things that bother you about your child?

Twelve (60%) mothers mentioned eating habits as problematic.

"The thing that bothers and worries me most is my child's eating habits. He insists on eating with his left hand, he is a glutton and he has a weight problem. Because he has type two diabetes, this causes many problems. Moreover, he has very bad sleeping habits. He refuses to go to bed and it always takes a lot of time to get him to bed". C

Five mothers (25%) reported that only the feeling that their children are different from others bothered them a lot.

"Sometimes I feel very bothered when I go anywhere with my child. I usually start to compare him with others. The feeling that my child is worthless and different from his peers bothers me a lot". R

Four (20%) reported that their children's stubbornness bothered them a great deal.

"Because my husband and I indulge our child too much, he has become very stubborn. He usually insists on doing what he wants. This bothers me a lot because I feel that we have taught him to act like that. Moreover, he is very attached to me which causes me a lot of problems because he refuses to do anything unless I ask him to". P

Two (10%) mothers declared that their children love their nannies more than them.

"Sometimes I am very upset because I feel that my child loves his nanny more than me. I feel that he does not realise that I am his mom, not her". S

One mother added a very different point of view:

"Seeing my child growing older really bothers me sometimes. Now she has a mature girl's body, but a little child's mind. This bothers me a lot because she is unaware that she should not show certain parts of her body, in accordance with our culture. But she can't understand that". N

#### 7.5.4.2. Do you feel that your child turned out to be more of a problem than you had expected?

Six mothers (30%) thought that their child caused fewer problems than they had expected.

"Sometimes I thought that my child would cause lots of problems. But in general, I think that he doesn't cause those problems which I expected". J

Eleven mothers (55%) thought that their children caused more problems than they had expected.

"Yes, I think that my child turned out to be more of a problem than I had expected, especially after the death of my husband. Too many problems arose with my husband's family concerning the child's inheritance". P

Finally, four mothers (20%) responded to this question that they were not sure.

"I am not sure about it. I believe that my child caused me lots of stress, but I am not sure if he caused more problems than I had expected". A

#### 7.5.4.3. Describe the relationship with your husband after the birth of this child?

Ten (50%) mothers reported that their relationship with their husbands had been very much affected by the child at first, but they believed that their relationship had now become stronger and better.

" At the beginning, we had lots of problems and arguments which changed our life completely. We decided to divorce, but because of God's will and my husband's family who lived with us at that time, we faced up to these problems and our relationship now is stronger and deeper". A

Four (20%) mothers thought that theire relationship with their husbands had become very bad after the birth of their children.

"My relationship with my husband has become extremely bad for many reasons. One of these reasons is having this child. We argue almost every day about him. We divorced three years ago, but got together again a year later" C.

Three mothers (15%) said that their child had strengthened their relationship with their husbands.

" I had a very strong relationship with my husband and it became stronger after the birth of this child. Moreover, we moved to live in another city that is far from our families, which has made our relationship stronger and we have become closer to each other". O

#### 7.5.4.4. Describe your social relationships after the birth of this child?

Six of the mothers (30%) reported that their social relationships became very poor after the birth of their children.

"In general I am not so sociable a person, but after the birth of this child, I became almost cloistered". P

Four (20%) said that their social relationships were confined to their families.

"I have almost no social relationships outside my family, my husband's family and a very few friends" T.

Four mothers (20%) reported that their social relationships were not as before the birth of their children, but they still have strong and good social relationships.

"My social relationships were affected a little bit because of my duties toward my family and my job, but I still have a good social relationship with friends and family" H.

Finally, six mothers (30%) responded that they still have as good social relationships as before.

"My social relationships were not affected at all by the birth of my child. This is because I live with my parents-in-law, who take care of the home and babysit my son when I go out" S.

### 7.5.4.5. Describe your relationship with this child compared to your other children, or to the relationship between any mother and her child?

For five mothers (25%) their relationship with their children did not differ from their relationship with their other children or from that between any mother and her typically developing child.

"I have a normal and healthy relationship with this child. I don't think that our relationship is different from any mother's with her normal child. Although I maybe worry about him more than any other mother, this doesn't mean that I don't care about his siblings or love them as much as I do him" J.

Four of the mothers (20%) thought that they had a different and strange relationship with their disabled child.

"My relationship with this child is very different from the one I have with her siblings. For instance, on her last birthday I was so sad, and when she reached adulthood, I cried and felt blue. I think I don't want her to grow up. Conversely I think in a very different way about her siblings. However, that doesn't mean that I don't love her or things like that. On the contrary, I do love her and care about her maybe more than any of my children, but in a very different way" N.

Two mothers (10%) said that their relationship with the child was poorer than other mothers because of their nannies.

" I depend on one qualified nanny to take care of this child. This makes him very attached to her. I think my relationship with my other children is stronger and deeper than with him" S.

Nine mothers (45%) confessed that they have a very strong relationship with their disabled child; stronger than with any other mother and child.

"I have a very warm and strong relationship with him. I am crazy about him and this relationship is stronger than any mother's is. Sometimes I think that I don't want to have any other children but him, because I don't want to get caught up with the other child" J.

## 7.5.5. Mental health:

Mothers were asked two questions about their mental health status, and whether they suffered from anxiety or depression, as follows:

### 7.5.5.1. To what extent do you feel haunted by anxiety, worry or frightened feelings?

All mothers recorded that they feel anxious and worried. Three (15%) of them reported that they had these feelings sometimes.

"Sometimes I feel anxious and worried about something vague. I don't know what. But when I am a haunted by these kinds of feelings, I immediately pray, because I do believe that these obsessions are from the devil" D.

Seventeen (85%) mothers reported that they have these feelings often.

"I always feel anxious and worried about things that may happen, almost every night before going to sleep. I am a haunted by these kind of feelings when I think about the future and things that may happen to us" Q.

#### 7.5.5.2.To what extent do you feel that you enjoy [your] life and the things you used to enjoy before the birth of your disabled child?

Twelve (20%) mothers believed that they do not enjoy their life and the things they used to enjoy at all.

"I don't have the same feelings about life. I don't enjoy the things that I used to enjoy before I had this child. I stopped doing many activities that I used to love, such as travelling with my husband without our children. In the past my husband and I liked to travel every year for two weeks without our children. It was a very enjoyable thing for both of us, but now, it is impossible to do it any more. And if we did, I would not enjoy it at all" O.

Eight mothers (40%) thought their situation better than others' and to some extent they enjoy life.

"Of course I don't enjoy it the same as I did before, but I think that I am much better than others. I still enjoy doing many things with my family and especially with my husband" H.

## 7.6. Discussion:

This study has reported many results, which can be combined with the findings in the literature. In this section we will summarise the results and then compare them with what has been found in the literature.

More than half of the mothers of ID children view the extended family in Saudi society as better than the nuclear family structure. These findings match results in the literature which have found that extended families provide good support (Byrne & Cunningham, 1985; Kwai-Sang Yau & Tsang, 1999; Mirfin-Veitch, Bray & Watson, 1997). Hwag and James (1999) focused on children from extended families, and found that they had fewer behavioural problems and less serious problems. Moreover, grandparents in extended families have indirect effects when they support the parents, especially with informal support (Mirfin-Veitch, Bray & Watson, 1997). Most of these mothers; in this study; focused on a specific type of support provided by their extended family and especially their parents or parents-in-law. Similarly, Sonnek (1986) reported that baby-sitting is one of the most instrumental supports provided by grandparents. However, some of the Saudi mothers in this study prefer not to share the same house but just to live nearby in the same buildings or compound. That means they prefer to live in a "modified extended family" rather than the original form of it. Sonnek (1986) and Abercrombie, Hill & Turner (2000) also reported that this kind of family is preferred in the United States and the United Kingdom.

Although some of the Saudi mothers in this study viewed their mothers-in-law as a source of stress, which was also reported in the literature, (e.g. Goeting, 1990; Sandler, 1998; Seligman et al., 1997), most of these mothers reported that their parents, parents-in-law and husbands are the most helpful resources for their coping and in raising their children (Goetting, 1990; Hastings, 1997; Seligman et al., 1997; Sonnek, 1986; Waisbern, 1980). Some of them reported that their families and their in-laws played no role, not because they were not helpful or they didn't want to help, but because they lived in different cities.

Most of the mothers have tried to take their minds off things by doing other things such as visiting relatives, shopping and watching television. However, they are trying hard to make their situation seem better, and almost all of them said that they have tried to make the best of their situations.

Although most of the mothers (90%) reported that they accepted their situation, some of them thought that they had only recently accepted it and believed it. Only few mothers appeared to be in a state of denial.
This might be one of the reasons that they do not use any medicine to make them feel better. They are trying all the time to deal with their situation and to cope with it.

All these mothers in the current research reported that they had received social support and technical support [from someone]. They reported that husbands and mothers or a member of their extended family were the people with whom they most commonly shared their concerns and interests, and with whom they had an emotional bond and to whom they had expressed their negative feelings (Baker, Landen & Kashima, 1991; Byrne & Cunningham, 1985; Dunst, Trivette & Cross, 1986; Gowen et al., 1989; Hastings, 1997; Kwai-Sang Yau & Tsang, 1999; Levy et al., 1996; Mogana, 1999; Sonnek, 1986; Sonuga-Barke, Thompson & Balding, 1993). In terms of the technical support they had received, they mentioned their child's doctor, the family doctor, the counsellor, workshops, and their children's teachers (Cotrell et al., 1988; Hellerand & Factor, 1993; Sonuga-Barke, Thompson, & Balding, 1993; Subotsky & Berelowitz, 1990).

More than half the mothers reported that they could see their situation in a different light and could make the situation seem better. Similarly, some previous studies reported that child disability can strengthen the family (e.g. Cunningham, 1982; Fewell, 1986; Glidden & Floyd, 1997; Kwai-Sang Yau & Tsang, 1999; Turnbull,1985; Turnbull, 1986).

More than half the mothers believed that their children caused more problems than they had expected (e.g. Beresford, 1996; Byrne & Cunningham, 1985; Epsten, 1987; Griest et al, 1980; Soliday, McCluskey & O'Brien, 1999), whereas some of them thought they had caused fewer problems than expected (e.g. Molsa & Molsa, 1985). Although disabled children sometimes do things that bother their mothers, such as in their eating habits, their stubbornness, or their attachment to their nannies, most of the mothers had normal relationships with their disabled children as well as with their TD children.

Concern and pessimism about their child's future, which looks uncertain and ambiguous for many mothers, was reported to place a great deal of stress on these mothers. Most of the previous studies also reported that fears about the future included where and how the disabled young adult would live (Hirst, 1982). However, concerns of parents undoubtedly change as their child grows older (Male, 1997) and the pessimism about the future was associated with an increase in the burden and depressive symptoms

(Dumas et al., 1991; Magana, 1999). With regard to these concerns about the future, this study's results reveal that only a quarter of the mothers try to plan for the future. Freedman and Seltzer (1997) noted that planning for the future could cause parents considerable anxiety. Hence, most parents do not make any long-term plans (Heller & Factor, 1991; Kaufman, Adams & Campbell, 1991; Seltzer & Krauss, 1994)

Mothers valued the role of religion in helping them to cope and stay healthy, and they viewed it as the best strategy for coping (e.g. Hastings, 1997; Frey, Greenberg & Fewell, 1989; Sonuga-Barke, Thompson, & Balding, 1993; Weisner, Beizer & Syolze, 1991; Zeitlin, Wiliamson & Rosenblatt, 1987). Whilst they are sure that it is not their fault, they sometimes blame themselves for their children's disabilities. Many studies in the literature also reported that parents are often ambivalent about the cause of their child's disability and this gives rise to self-blame and guilt in the parents of disabled children (e.g. Breslau & Davis, 1986; Hawkins & Cooley, 1987; Meyerson, 1983; Nixon & Singer, 1993). Moreover, most of them do not have a sense of humour about their children disabilities; they cannot make fun of their situation.

Although some of the mothers reported that their marital relationship was affected after the birth of their disabled children (Byrne & Cunningham, 1985; Friedrich & Friedrich, 1981; Lavee, Sharlin & Kazak, 1996), more than half of them reported their relationship with their husbands to be stronger and better than in the past (Abbott & Meredith, 1986; Byrne & Cunningham, 1985; Kwai-Sang Yau & Tsang, 1999; Longo & Bond, 1984). They believe that their disabled child has strengthened their relationship with their husbands. Moreover, mothers' social relationships were affected badly after the birth of their disabled children. This result replicates the findings in the literature that parents of disabled children appear to have a smaller social network than families with TD children (e.g. Beresford, 1996; Epstein, 1987; Gabel & Swartz Kotsch, 1981; Kazak & Marvin, 1984; McDowell & Gabel, 1981; Mirfin-Veitch, Bray, & Watson, 1997; George, 1988; Sandler, Warren & Raver, 1995; Schilmoeller & Baranowski, 1998; Sonnek, 1986;).

Most of the mothers see themselves as anxious and worried most of the time or at least sometimes (e.g. Beebe, Casey & Pinto-Martin, 1993; Floyd & Philiippe, 1993; Krauss, 1993; Molsa & Molsa, 1985; Thome & Adler, 1999;), and they do not enjoy life and the things that they used to enjoy.

In conclusion, this study has pointed to many issues that are important to know before continuing the research.

1. The study gives a clear idea about the mothers in this specific society, and of what they think about themselves, their husbands, their families, and their children's disability. Moreover, it gives a clear idea of their stressors and the coping strategies most of them use.
2.The results indicate that the researcher should add a further questionnaire about family support because all the participants stressed the role of family support. Hence, the FSS (Dunst et al., 1993) will be used along with the other scales.
3.As a result of the mothers' responses during the interviews, a few items in the questionnaires will need to be changed to make them more appropriate to this culture. For example, items asking about the use of alcohol or other drugs will be replaced by 'use of medicines such as tranquillisers or sleeping pills'.
3. The researcher will delete some words in the questionnaires because the fact they were not used by the mothers in their responses indicates they are inappropriate. For example, going to cinema: since there are no cinemas or theatres in Saudi Arabia, these words are inappropriate to this sample. All items that used 'partner' were deleted because it is illegal in Saudi Arabia to live together without being married.
4. Since religion was viewed as the most important coping strategy by all of the mothers, some items have been added to the questionnaires. For example, two items about religion have been added to the Brief COPE scale

5. Some items should be rephrased. For example, Item 9 in the HADS scale (see Appendix 8) will be rephrased because 'butterflies in stomach' is found to be an unclear expression. The item 'praying or mediating' is rephrased to 'praying and invocation'.

# CHAPTER 8

# TRANSLATION PROCESS (STUDY 2)

## 8.1.Introduction:

Many potential research participants lack competence in English (Perczek, Carver & Price 2000). Moreover, the differences between cultures makes translation into other languages necessary. There was a need to translate the questionnaires in this study because very little work had been done on any community aspect of mental health problems in Saudi Arabia (Akhdar, 1995). Thus, there is a shortage of Arabic translations of questionnaires in this field. This made the translation of the questionnaires that were going to be used in the main study very important for this study.

## 8.2.Significance of the study:

The instruments that are going to be used in the main study have been translated into many languages, such as Spanish (Solis & Abidin, 1991; Preczek, Carver & Price, 2000), Italian (Glombok, 1996), French (Bigras, 1996; Cameron, 1989; Levin & Banks 1991) Portugese (Viera, 1994 & Viera et al., 1996), Chinese (Huang, 1998; Ong et al., 1998; Scott et al., 1997; Tam et al., 1994 & Tsang et al., 1992), and Japanese (Holady et al., 1997& Nakagawa et al., 1992). However, there were no Arabic (Saudi) language psychological instruments designed to assess levels of parenting stress, coping, and social support.

This study will be significant in a number of ways:

*First:* The study is the first of its type to translate the Brief COPE, SPS, and FSS into Arabic.

*Second,* The study is the first of its type to measure the validity and reliability of an Arabic version of the instruments. Moreover, it is the first study to measure the reliability and the validity of the PSI-SF & the HADS in Saudi culture.

## 8.3.Purpose of the study:

The general purpose of this study is to establish scales that measure stress, coping, and social support in Saudi culture.

To achieve the goal of this study, the following specific research questions are identified and addressed:

1. What is the reliability and validity of the Arabic translation of the Brief COPE?
2. What is the reliability and Validity of the Arabic translation of the Social Provision Scale (SPS)?
3. What is the reliability and validity of the Arabic translation of the Family Support Scale (FSS)?
4. What is the reliability and validity of the Arabic translation of the Parenting Stress Index-Short Form (PSI-SF)?
5. What is the test-retest correlation for the Hospital Anxiety and Depression Scale (HADS) and especially for the ninth item (I get sort of frightened feeling like "butterflies" in the stomach) because it was not significant when translated in Arabic (El-Rufaie, 1987)?

## 8.4.Instruments:

The HADS: (Zigmond, and Snaith, 1983). Translated by El- Rufaie (1987), the PSI-SF (Abidin,1995), the Brief COPE (Carver, 1997), the SPS (Cutrona and Russell, 1987), the FSS (Dunset, Jenkins , and Trivette, 1993), and the demographic data scale. These instruments have been described in more detail in Chapter 6.

## 8.5.Procedures:

### 8.5.1. Translation process:

As mentioned in Chapter 6 in translating this study's questionnaires, the researcher followed Vallerand's (1989) methodology in the cross-cultural psychology field. He suggested seven steps to follow for the translation and validation of an instrument (see Chapter 6).

1. Preparation of preliminary version.
2. Evaluation of preliminary version and preparation of an experimental version.
3. Pre-test of an experimental version
4. Evaluation of the content and concurrent validity
5. Reliability analyses
6. Evaluation of the construct validity
7. Establishing norms

## 8.6. Results:

### 8.6.1.Step 1: Initial translation:

After obtaining the authors' permission to use their instruments and translate them into Arabic, the researcher translated the Brief COPE, FSS and the SPS very carefully. I tried to avoid literal translation, but translated the meaning of the statements as a whole unit, rather than using a word-for-word translation. The translation of the PSI-SF was checked. A bilingual individual was then asked to perform the initial translation of the three instruments from the original language (English) to the target language (Arabic). This person is fluent in both languages and has a Master's degree in English-Arabic translation. The translator is from Saudi Arabia. This meant that she had the experience of living in the culture and could avoid non-accurate translations (such as items about going to cinemas drinking alcohol, etc). According to Brislin (1980), familiarity with the culture is an important factor in determining the quality of the translation. This person was asked to translate the questionnaires as close to the original as possible. Then, the comparison between the researcher's translation and this new translation was made. A few alterations were needed at this stage as both translators agreed on the language to be used.

**a. Back translation:**

The Arabic translation resulting from the first step was given to another bilingual who has a Ph.D. in psychology from the U.S.A, and is experienced in translation. He was asked to back translate the three Arabic questionnaires into English.

**b. Comparison and revision:**

The original PSI-SF, SPS, Brief COPE, FSS and the back-translated English versions, which resulted from the previous step, were compared by the back-translator to check for mismatches. The translator either agreed to keep one version in the case of mismatches, or agreed a revision designed to address any ambiguities. Some minor discrepancies were detected and fixed via this process.

### 8.6.2. Step 2: Evaluation of preliminary version and preparation of an experimental version:

This step was an adaptation of the committee approach described by Vallerand.

**a. Committee approach:**

According to Brislin (1980) some researchers indicated that this approach could be used independently. However, in this study the approach was included as an additional step to further improve the quality of the translation. The research committee consisted of three professors from the psychology department of Um-Al Qura University. All of them had graduated in the U.S.A, and were experienced in translation. The committee was provided with both the original forms of the Brief COPE, PSI-SF, SPS, FSS and the Arabic versions resulting from the step above. Upon comparing the two versions, the committee approved the translation and confirmed its appropriateness and accessibility to the Arabic reader. After minor revisions were made an experimental version was produced.

### 8.6.3. Step 3: Pre-test of experimental version:

This step consisted of two main subordinate steps as follows:

#### a. Field test (pilot testing):

The final Arabic versions of the Brief COPE, PSI-SF, SPS, and FSS were administered to a group of 25 mothers of TD and ID children In Saudi Arabia. Mothers were recruited from special education and TD schools. Eighty-eight percent of the mothers were married and 12% were widowed. Seventy-two percent of them were housewives. Their level of education was M= 12.48 SD= 4.38. The mean number of children in each family was 4.28 SD=1.83. The age of the children was M=7.54 SD= 2.52. Seventy-two percent of the children were males and 28% were females. Twenty percent of the children were non-disabled, 36% had Down's syndrome, 20% had Autism, 8% cerebral palsy, 8% fragile X syndrome, 8% moderate disability with unknown aetiology. Participants were first asked to complete the experimental versions and to indicate directly on the questionnaire words or expressions they did not understand or felt uncomfortable with by underlining them. Also, they were asked that if they had any suggestions to write them down directly next to the statements.

In several studies (Prieto, 1992; Bin Batal, 1998) researchers tested the reliability of the questionnaires using Cronbach's alpha coefficient at this stage. However, Vallerand (1989) argued that no statistical tests should be performed at this time.

#### b. A study of bilingual Participants (Validity):

At the next stage, the researcher used another technique to test the validity and reliability of the translated questionnaires. This technique has been used before by many researchers (Benville, 2000; Sperber et al., 1994; Vallerand, 1989). This step involved the use of participants proficient in both languages to pilot the instruments (Benville et al., 2000).

Thirty questionnaires had been sent to bilingual participants who had been recruited for this step. The participants were postgraduate students in linguistics, English teachers, doctors who worked in the King Abdulaziz hospital in Jeddah and ARAMCO company employees who had graduated in the USA and were skilled in the English language. All of the participants were Saudi, so Arabic is their first language.

Seventy one percent (71.4 %) of the sample were male and 28.6% were female. Their mean age was 32.85, SD=6.26. All of the participants were married and working away from home. 10.7% of the whole sample were English teachers, 37.7 % were ARAMOCO employees, 39.3% were doctors in the King Abdullaziz Hospital, and 14.3% were post graduate students.

To ensure that all participants were sufficiently bilingually skilled, a self-evaluation test, developed by Vallerand (1983) and used by Banville et al. (2000) was administered. This test asks about the participant's ability to understand, read, write, and speak the two languages involved by giving themselves a score from 1 (very little) to 4 (perfectly) for each component (see Appendix 3). A score of 12 or more is judged acceptable for each language (Banville et al., 2000). Participants should score at least 3 in each sub-domain to be viewed as functionally bilingual.

Self-evaluation test results showed only six participants (21.4%) had 12 out of 16, meaning their English language was Good. Eight participants (28.6%) had 13-14 out of 16, which meant their language was very good. Finally, 14 participants had 15-16 out of 16, which meant their language was excellent. These results meant that they had an acceptable language level according to the Vallerand's evaluation test.

All participants scored 15-16 out of 16 in the Arabic self-evaluation test. This meant their Arabic was excellent. These results indicated a perfect language level.

Half of the participants completed the Arabic versions of the measures first, and half of them completed the English versions first. Then the thirty participants returned the first questionnaires and about two weeks later the opposite versions of the same scales were sent to them. Only 28 participants returned the second questionnaire. The participants have been included in the data analysis that assessed dimensions of reliability and validity. In some studies that have used this technique, participants were grouped in one room, filling in both questionnaires at the same time (Banville et al., 2000).

### 8.6.4. Step 4: Evaluation of the concurrent and content validity:

Two types of validity were explained in this step: content validity and concurrent validity.

**a. Content validity** is defined as a qualitative assessment of content (Berg & Latin, 1994). The committee assessed the accuracy of the translated statements by measuring the concept associated with each statement. The meaning of the original statements and the Arabic statements had to be identical. Three statements were judged to be completely inappropriate for Saudi society: asking about the use of alcohol, going to the cinema, and support from a "partner". Two statements were added to the Brief COPE. According to the pilot study results, mothers referred to fate and destiny and rewards from God as coping mechanisms. These two things were viewed as very important in Saudi society but they were not included in the original version of the Brief COPE and so were added.

**b. Concurrent validity:** according to Berg and Latin (1994) this kind of validity aims at correlating test results of the new instrument with an already valid instrument. Since the Brief COPE, the SPS and the PSI-SF had already been validated, the scores of the original and the experimental version would be compared using two tests as follows:

1. A paired t-test (a non-significant "p" will indicate similarities of the statements) (Vallerand, 1983).
2. A Pearson correlation (a high correlation will indicate similarities of the statements) (Banville et al., 2000).

**1. A paired t-test:**

Results revealed that there were no significant differences between the original version (English) and the experimental (Arabic) versions of all questionnaires. For the Brief COPE (t=. 95, df=27,p=. 34,two-tailed), for the SPS (t=1.03, df=27,p=. 13, two-tailed), for the FSS (t=. 41,df=27,p=. 68, two-tailed), and for the PSI-SF (t=1.83, df=27, p=. 08, two-tailed). That meant the experimental (Arabic) versions were very compatible, (see Tables 1 & 2)

Table 1: Mean differences and SD of English and Arabic scales and subscales

| | M | SD | No. |
|---|---|---|---|
| Brief COPE | 75.42 | 7.81 | 28 |
| Arabic Brief COPE | 74.75 | 7.45 | |
| SPS | 78.64 | 8.85 | 28 |
| Arabic SPS | 79.67 | 8.18 | |
| FSS | 36.96 | 13.89 | 28 |
| Arabic FSS | 37.35 | 13.57 | |
| PSI | 81.67 | 20.83 | 28 |
| Arabic PSI | 78.78 | 20.70 | |

Table 2: t-test of the Brief COPE, SPS, FSS, and PSI-SF

| | t | Sig. |
|---|---|---|
| Brief COPE | .95 | .34 ns |
| SPS | -1.52 | .13 ns |
| FSS | -.41 | .68 ns |
| PSI-SF | 1.83 | .08 ns |

**2. A Pearson correlation:**

Results indicate that there were significant positive correlations between the English and the Arabic versions of all the questionnaires. Correlation was high (p<.01) for all questionnaires, for the Brief COPE, for the SPS , for the FSS, and for the PSI-SF (Table 3).

Table 3: Correlation between English and Arabic versions

| | Correlations | N of cases | N of items |
|---|---|---|---|
| Brief COPE | .88** | 28 | 28 |
| SPS | .91** | 28 | 24 |
| FSS | .93** | 28 | 18 |
| PSI-SF | .95** | 28 | 36 |

**Correlation is sign. at a 0.01 level

Table 4 reveals that there are significant levels of correlations from .58 to .94 on all English and Arabic Brief COPE subscales. However, there were only two items which did not meet the level of significance: "active coping", and "Acceptance". These two items showed low and insignificant levels of correlation. "active coping" (r= .30,n= 28, p=ns) and "acceptance" (r= .26, n=28, p=ns).

Table 4: Correlation between English and Arabic Brief COPE sub-scales

| Sub-scales | Correlation | N of cases | N of items |
|---|---|---|---|
| 1. Self distraction | .90** | 28 | 2 |
| 2. Active Coping | .30 ns | 28 | 2 |
| 3. Denial | .68** | 28 | 2 |
| 4.Substance use | .58** | 28 | 2 |
| 5. Use of emotional Support | .87** | 28 | 2 |
| 6. Use of instrumental support | .85** | 28 | 2 |
| 7. Behavioural Disengagement | .70** | 28 | 2 |
| 8.Venting | .73** | 28 | 2 |
| 9. Positive Reframing | .75** | 28 | 2 |
| 10. Planning | 92** | 28 | 2 |
| 11. Humour | .94** | 28 | 2 |
| 12. Acceptance | .26 ns | 28 | 2 |
| 13. Religion | .92** | 28 | 2 |
| 14. Self Blame | .91** | 28 | 2 |

**Correlation is sign. at a 0.01 level

Table 5 shows that there was a highly significant level of correlation between the English and Arabic PSI-SF subscales.

Table 5: English and Arabic PSI-SF sub-scales correlation

| Sub-scales | Correlation | N of cases | N of items |
|---|---|---|---|
| 1. Parental distress (PD) | .93** | 28 | 12 |
| 2. Parent-child dysfunctional interaction (P-CDI) | .91** | 28 | 12 |
| 3. Difficult child (DC) | .98** | 28 | 12 |

**Correlation is sign. at a 0.01 level

Table 6 shows that English and Arabic SPS subscales demonstrated significant levels of correlation from .52 to .93.

Table 6: English and Arabic SPS sub-scale correlation

| Sub-scales | Correlation | N of cases | N of items |
|---|---|---|---|
| 1. Guidance | .93** | 28 | 4 |
| 2. Reassurance of worth | .87** | 28 | 4 |
| 3.Social integration | 82** | 28 | 4 |
| 4. Attachment | .62** | 28 | 4 |
| 5. Nurturance | .85** | 28 | 4 |
| 6. Alliance | .52** | 28 | 4 |

**Correlation is sign. at a 0.01 level

Table 7 shows a high level of correlation between English and Arabic FSS subscales. The correlations ranged from .76 to .98.

Table 7: English and Arabic FSS sub-scale correlation

| Subscale | Correlation | N of cases | N of items |
|---|---|---|---|
| Husband support | .76** | 28 | 3 |
| Informal kinship | .89** | 28 | 5 |
| Formal kinship | .98** | 28 | 2 |
| Social organization | .91** | 28 | 4 |
| Professional services | .88** | 28 | 4 |

**Correlation is sign. at a 0.01 level

## 8.6.5. Step 5: Evaluation of reliability:

In this step two methods of establishing reliability have been used: internal consistency using Cronbach's alpha, and test-retest reliability.

### a. Internal Consistency:

Table 8 shows that all of the four experimental scales obtained alphas between .76 and .94, which values are also similar to those found in the original versions.

Table 8: Cronbach's alpha test for English and Arabic questionnaires

|  | Alpha | N of cases | N of items |
|---|---|---|---|
| Brief COPE | .78 | 28 | 28 |
| Arabic Brief COPE | .76 | 28 | 28 |
| SPS | .94 | 28 | 24 |
| Arabic SPS | .94 | 28 | 24 |
| FSS | .91 | 28 | 18 |
| Arabic FSS | .89 | 28 | 18 |
| PSI-SF | .91 | 28 | 36 |
| Arabic PSI-SF | .93 | 28 | 36 |

Table 9 shows acceptable alpha levels for the Brief COPE English version between .57 to .96 and for the Brief COPE Arabic version between .55 and .93.

Table 9: The internal consistency of English and Arabic Brief COPE subscale

| Subscales | | Alpha | N of items |
|---|---|---|---|
| 1. Self-blame | English | .87 | 2 |
| | Arabic | .87 | 2 |
| 2. Active coping | English | .57 | 2 |
| | Arabic | .65 | 2 |
| 3. Denial | English | .57 | 2 |
| | Arabic | .80 | 2 |
| 4. Substance use | English | .88 | 2 |
| | Arabic | .65 | 2 |
| 5. Use of emotional support | English | .64 | 2 |
| | Arabic | .55 | 2 |
| 6. Use of instrumental support | English | .91 | 2 |
| | Arabic | .76 | 2 |
| 7. Behavioural disengagement | English | .92 | 2 |
| | Arabic | .72 | 2 |
| 8. Venting | English | .61 | 2 |
| | Arabic | .55 | 2 |
| 9. Positive reframing | English | .68 | 2 |
| | Arabic | .69 | 2 |
| 10. Planning | English | .76 | 2 |
| | Arabic | .68 | 2 |
| 11. Humour | English | .86 | 2 |
| | Arabic | .88 | 2 |
| 12. Acceptance | English | .90 | 2 |
| | Arabic | .83 | 2 |
| 13. Religion | English | .91 | 2 |
| | Arabic | .93 | 2 |
| 14. Self blame | English | .96 | 2 |
| | Arabic | .93 | 2 |

Table 10 shows a high level of alpha for PSI-SF English and Arabic sub-scales. All of the PSI-SF sub-scales exceeded an alpha level of .86 or higher.

Table 10: The internal consistency of English and Arabic PSI-SF subscales

| Subscales | | Alpha | N of items |
|---|---|---|---|
| 1.Parental distress (PD) | English | .86 | 12 |
| | Arabic | .87 | 12 |
| 2.Parent-child dysfunctional interaction (P-CDI) | English | .90 | 12 |
| | Arabic | .90 | 12 |
| 3. Difficult child (DC) | English | .88 | 12 |
| | Arabic | .90 | 12 |

Table 11 demonstrates a satisfactory alpha level for both English and Arabic SPS sub-scales. Alpha was between .60 to .81 for the English version, and .75 and .85 for the Arabic.

Table 11: The internal consistency of English and Arabic SPS Subscales

| Subscales | | Alpha | N of items |
|---|---|---|---|
| 1. Guidance | English | .81 | 4 |
| | Arabic | .85 | 4 |
| 2. Reassurance of worth | English | .74 | 4 |
| | Arabic | .79 | 4 |
| 3. Social integration | English | .71 | 4 |
| | Arabic | .76 | 4 |
| 4. Attachment | English | .60 | 4 |
| | Arabic | .81 | 4 |
| 5. Nurturance | English | .76 | 4 |
| | Arabic | .75 | 4 |
| 6. Reliable alliance | English | .69 | 4 |
| | Arabic | .77 | 4 |

Table 12 reveals that there was a satisfactory alpha level of all English and Arabic FSS sub-scales from .42 to .85.

Table 12: The internal consistency of English and Arabic FSS subscales

| Subscale | | Alpha | N of items |
|---|---|---|---|
| 1. Husband support | English | .42 | 3 |
| | Arabic | .51 | 3 |
| 2. Informal kinship support | English | .83 | 5 |
| | Arabic | .75 | 5 |
| 3. Formal kinship support | English | .85 | 2 |
| | Arabic | .85 | 2 |
| 4. Social organisation | English | .75 | 4 |
| | Arabic | .78 | 4 |
| 5. Professional services | English | .79 | 4 |
| | Arabic | .79 | 4 |

The previous tables showed that all the subscales for all the questionnaires obtained high alpha in both versions. However, in the Brief COPE four of the subscales were under the values recommended by Vallerand (1989): "active coping", "denial" in the Arabic versions, and "use of emotional support" and "venting" in the English version. These four items obtained alpha below the recommended value. However, they were very near to achieving .60. Also in the FSS, the "husband support" subscale obtained .42 for the Arabic version and .51 for the English version, which were lower than other subscales within the same questionnaire.

### b. Test- retest reliability:

In this stage, 25 questionnaires were sent to mothers of TD children. Mothers were recruited from kindergarten and elementary school. Their mean age was 31.18 (SD=4.22). The mothers' mean level of education was 12.77 (SD=4.29). 59.1% of them were housewives. 90.9% of them were married and 9.1% were divorced. 45% of the children were male and 54% were female. The children's mean age was 6.51 (SD=2.16). Mothers were asked to complete the demographic data and the questionnaires which all 25 completed and returned. Moreover, the HADS scale has been added at this stage in order to find its test-retest correlation, because in the El-Rufaie study (1987), when measuring the item subscale correlations, all items in both subscales were highly significant (p< 0.001) except for the ninth item "I get a sort of frightened feeling like butterflies in the stomach". Similarly, all items except the ninth had a highly significant correlation (P< 0.001) with the author's ratings of the respective mood disorder. El-Rufaie (1987) reported that this item (from the anxiety subscale) was the only unreliable item. However, this did not affect the overall validity of the scale. He put this down to the difficulty of translating colloquial English. He recommended future users of the scale to substitute a different, although similar expression referring to a sensation of fear centred in the epigastric region. Only this item was slightly changed in this study. Because this item was a kind of English idiom which has no synonym in the Arabic language, the researcher tried to explain it better in order to make it clearer. The new item was then presented to two bilinguals in order to check the validity of the translation. After slight changes, the new item was added to the translated scale. Therefore, the HADS has been added at this stage in order to test the test re-test reliability for the new item and for the whole scale because in previous studies the test-retest reliability for the HADS has not been measured (El-Rufaie, 1987; El-Rufaie, 1995). Then, about two weeks later, the same version of all questionnaires was sent again to all the mothers. Only 21 mothers returned the second questionnaires, so only those 21 participants were included in analysing data. Correlations for the test-retest were tested.

Table 13 shows the correlation between the test-retest for the Brief COPE, PSI-SF, SPS, and FSS. Correlation was highly significant for all the questionnaires ranging from .74 to .96.

Table 13: Test-retest correlation between Arabic questionnaires

| Scale | Correlation |
|---|---|
| 1. Brief COPE | .92** |
| 2.PSI-SF | .94** |
| 3.SPS | .74** |
| 4.FSS | .94** |
| 5.HADS | .96** |

**Correlation is sign. at a 0.01 level

Table 14 presents test- retest correlation of the Brief COPE Subscales. The table showed significant correlations of all sub-items from .59 to .98.

Table 14: Test-retest correlation between Arabic Brief COPE subscales

| Subscales | Correlation |
|---|---|
| 1. Self distraction | .86** |
| 2. Active coping | .77** |
| 3. Denial | .88** |
| 4. Substance use | .98** |
| 5. Use of emotional support | .92** |
| 6. Use of instrumental support | .59** |
| 7.Behavioural disengagement | .94** |
| 8. Venting | .84** |
| 9. Positive reframing | .83** |
| 10. Planning | .84** |
| 11. Humour | .96** |
| 12. Acceptance | .84** |
| 13. Religion | .82** |
| 14. Self blame | .85** |
| 15. Religious beliefs | .58** |

**Correlation is sign. at a 0.01 level

Table 15 presents test- retest correlation of the PSI-SF. A correlation was highly significant for all the three sub-scales ranging from .90 to .88.

Table 15: Test-retest correlation between PSI-SF subscales

| Subscales | Correlation |
|---|---|
| 1. Parental distress (PD) | .88** |
| 2. Parent-child dysfunctional interaction (P-CDI) | .90** |
| 3. Difficult child (DC) | .83** |

****Correlation** is sign. at a 0.01 level

Table 16 presents the test-retest correlation of the SPS. All the sub-scales obtained a high level of significance, with a correlation from .70 to .91.

Table 16: Test-retest correlation between SPS subscales

| Subscales | Correlations |
|---|---|
| 1. Guidance | .70** |
| 2. Reassurance of worth | .89** |
| 3. Social integration | .87** |
| 4. Attachment | .88** |
| 5. Nurturance | .70** |
| 6. Reliable alliance | .91** |

**Correlation is sign. at a 0.01 level

Table 17 shows a high correlation between the test-retest of SPS sub-scales from .77 to .94.

Table 17: Test-retest correlations between FSS subscales

| Subscales | Correlations |
|---|---|
| 1. Husband support | .77** |
| 2. Informal kinship support | .94** |
| 3. Formal kinship support | .84** |
| 4. Social organizations | .79** |
| 5. Professional services | .89** |

**Correlation is sign. at a 0.01 level

Table 18 shows the last results in the test-retest correlation. It showed a very high correlation between the test-retest of the HADS sub-scales, .98 for anxiety and .95 for depression.

Table 18: Test-retest correlation between HADS subscales

| Sub-scales | Correlations |
|---|---|
| 1. Anxiety | .98** |
| 2. Depression | .95** |

**Correlation is sign. at a 0.01 level

### 8.6.6. Step 6: Evaluation of the construct validity:

According to Vallerand, the main objective of this step is to verify that the translated instrument measures what is defined in the literature. This demonstrates that the theory underlying the instrument is applicable to other cultures (Vallerand, 1989). Moreover, it can be verified by studying the structure of the instrument's 'interscale correlation' (Banvile, Desrosiers & Genet-Volet, 2000).

Since an interscale correlation was performed with the Brief COPE, SPS, FSS and PSI-SF and assumptions were made concerning links between subscales, the strategy used was an interscale correlation with the experimental versions and a comparison of the results with those obtained in the original versions (Ennis & Chen, 1995).

Table 19 presents correlations between the English questionnaires. All the questionnaires were found to correlate to each other from .40 to .60. However, the English version of the FSS did not correlate significantly with the Brief COPE, SPS, and PSI-SF.

Table 19: Correlation between English questionnaires

| | COPE | SPS | FSS |
|---|---|---|---|
| Brief COPE | 1.00 | .40* | .28 |
| SPS | .40* | 1.00 | .21 |
| FSS | .28 | .21 | 1.00 |
| PSI-SF | -.52** | -.60** | -.27 |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level

Table 20 demonstrates that all of the Arabic version scales showed a significant level of correlation from .40 to .62.

Table 20: Correlation between Arabic questionnaires

| | A. COPE | A.SPS | A.FSS |
|---|---|---|---|
| A. Brief COPE | 1.00 | .41* | .42* |
| A.SPS | .41* | 1.00 | .40* |
| A.FSS | .40* | .40* | 1.00 |
| A.PSI-SF | -.41* | -.62** | -.26 |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level

A further procedure was taken at this stage, to test the correlation between each Arabic scale with other English scales. Results in Table 21 show that there was a correlation between the Arabic Brief COPE and the English versions of Brief COPE, PSI-SF but not with the English version of SPS and FSS. The English version of the Brief COPE did not significantly correlate with FSS. The Arabic SPS correlated significantly with all of the English scales. On the other hand the English SPS only correlated significantly with the Arabic version of SPS and PSI-SF. The Arabic FSS only correlated significantly with the English version of FSS. However, the English version of the FSS correlated significantly with the Arabic version of FSS and SPS. Finally, the Arabic PSI-SF correlated with the English PSI-SF, SPS, and the Brief COPE 'from. -.52 to .96 but not with the English FSS. The English PSI-SF also correlated with the Arabic PSI-SF, SPS and

Brief COPE from '-.40 to .96', however it did not correlate significantly with the Arabic FSS.

Table 21: Correlation between English and Arabic questionnaires

| | A. Brief COPE | A.SPS | A.FSS | A.PSI-SF |
|---|---|---|---|---|
| Brief COPE | .88** | .47* | .31 | -.52** |
| SPS | .31 | .91** | .27 | -.62** |
| FSS | .29 | .37* | .93** | -.23 |
| PSI-SF | -.40* | -.64** | .25 | .96** |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level

### 8.6.7. The next step: Establishing norms:

The last step of the translation process was establishing norms. Vallerand (1989) used simple statistics such as averages, standard deviations, percentile rank, and T and Z scores. This step should be done when the instrument has been judged valid, reliable, and meaningful in the new culture. Moreover, in order to establish norms, a large number of participants would be needed (Banvile et al., 2000). The PSI-SF, Brief COPE, SPS, FSS and the HADS will be included in the normative study. Descriptive statistics, correlations, Cronbach's alpha and factor analyses were used at this stage. The next study will discuss this step in detail.

## 8.7.Discussion:

All of the questionnaires that have been used in this study have shown significant levels of reliability and validity when used with the Saudi sample. The PSI-SF showed a high level of reliability and validity when used with the Saudi sample, compared to the original study (Abidin, 1995), the results from the two samples were convergent. Test-retest reliability and alpha coefficients were calculated based on the entire normative sample of 800 participants. Results showed that the PSI-SF is highly reliable for total stress, for parental distress, for parent-child dysfunctional interaction (P-CDI), and for difficult child (DC) (Abidin, 1995). Moreover, Roggman, Moe, Hart, and Forthun (1994) studied 103 participants and also reported high PSI-SF high alpha reliabilities. Validity of the questionnaire was tested by using the correlation between PSI-SF and the full length PSI for a sample of 530 participants. They also reported a high level of validity. Abidin (1995) believed that because the PSI-SF is a direct derivative of the full-length PSI, it is likely that it will share the validity of the full-length PSI. Compared to the previous studies' results, the PSI-SF showed a high level of reliability and validity when used with the Saudi sample. Non-significant t-test revealed similarities between the English and the translated questionnaire and high levels of correlation between English and Arabic PSI-SF and moreover, a high level of Cronbach's alpha for the whole scale, and subscales. Test-retest reliability was also very high for the whole scale, and for subscales. Then correlation of the Arabic PSI and other scales was tested. The Arabic PSI-SF was correlated significantly with the Arabic Brief COPE, and the SPS, but not with the FSS. The previous validity and reliability results for Abidin's study (1995) related closely to what has been found in the results of this study. Moreover, the current study revealed highly significant results for all the tests that were used. That means the questionnaire is appropriate to use with the Saudi sample and it will give a valid and reliable result.

The Brief COPE showed good levels of reliability and validity compared to the initial study (Carver, 1997), which used the Brief COPE with survivors of hurricane Andrew. The translated Brief COPE proved to be reliable and valid. Compared to the English version, the Arabic Brief COPE had a non-significant t-test, which means the two versions gave similar mean scores. When we tested the Pearson correlation between both versions, correlation was significant, and all the sub-scale correlated significantly except for active coping (.30) and acceptance (.26). This study also indicates that a priori scales have adequate alpha measures for the English and for the Arabic version. As can be seen for the main study (Carver, 1997) and this study's results, despite the fact that the scales are only two items each, their reliability met or exceeded the value of .50 regarded as minimally acceptable by Nunnally, 1978 (cited in Carver, 1997). Indeed, all exceeded .60 except for "venting", "denial", and "acceptance" in the main study (Carver, 1997) and for "active coping" and "denial", in the original questionnaire (English) and "use of emotional support" and "venting" in the experimental questionnaires (Arabic) in the present study. This showed that there is a good relationship between the results of this study compared to Carver's. When using the test-retest reliability, correlation was very high for the whole scale and for the sub-scales. Finally, when we correlated it with the other scales, the Arabic Brief COPE showed a significant correlation with the PSI-SF, and with the FSS, whereas it significantly correlated with the English Brief COPE and the English PSI. These results proved that the translation of this scale was acceptable and reliable and valid with the Saudi participants.

The reliabilities of individuals, SPS are adequate. The reliability of the total social provisions score was high. The construct validity of the instrument is supported by findings concerning the relationship between the social provision scale and measures of social support which include the social support questionnaire (Sarason et al., 1983), the index of socially supportive behaviors (Barrera et al., 1981), and a measure of attitudes towards use of social support (Eckenrode, 1983). All correlated highly to the social provision scale. Also, the results of the original study of the SPS showed high reliability for the total scale. The authors revealed a high correlation in tested test-retest reliability for the total scale score and for the sub-scales (Cutrona & Russel, 1987).

When used with the Arabic sample, the SPS showed a non-significant t-test, which means the means for the two versions did not differ. Correlation between the English and the Arabic SPS was highly significant, and also for the subscales. Internal consistency showed a high level of alpha for the whole Arabic scale and for the subscales. Moreover, test-retest analysis results also showed a significant correlation for the whole scale and for the sub-scales. Finally, the Arabic SPS correlated significantly with the Arabic Brief COPE, FSS, and PSI-SF. All the current study results indicate that the Arabic translated SPS was highly reliable and valid when used with the Arabic sample. These results were parallel to what has been found in the study, which means the scale is appropriate for use with the Arabic population.

In the FSS original study (Dunst, Trivett & Hamby, 1993) internal consistency for the scale and subscales was adequate. Test-retest reliability was significant for the total scale score and for separate items. When used with the current sample the FSS showed a non-significant t-test and that means the English and Arabic scales were the same and did not show significant differences. English and Arabic correlations for the whole scale was highly significant and there was also a high level of significance for the subscales. Test-retest reliability revealed a high correlation for the whole scale and for the subscales. When measuring the relationship between the FSS and the other scales, it was revealed that the Arabic version of FSS correlated significantly with the Arabic Brief COPE, the Arabic SPS, but not with the Arabic PSI-SF. This study result emphasised that the Arabic version of FSS is a highly reliable and valid instrument, and it can be used with the Arabic sample.

Finally, when we added the HADS in the test-retest reliability, it showed the highest level of correlation of all the scales, for the complete scale, and for the sub-scales. The ninth item, which was not significant in the original study (I get a sort of frightened feeling like "butterflies" in the stomach) showed a highly significant correlation with all items in the first test and in the retest. That means the new translation of this item is better than the previous one.

# CHAPTER 9

# THE MAIN STUDY, INTRODUCTORY STEP (STUDY 3)

## 9.1. Introduction:

This chapter is considered as a link between the previous and the following chapters. It tried to confirm what we have done in Chapter 8 with large samples of mothers of typically developing (TD) and intellectually disabled (ID) children. Moreover, it provided the elementary information needed in Chapter 10: the participants, questionnaires and data were the same as those in Chapter 10.

## 9.2. Purpose of the study

The aim of the current study was to assess the equivalence of Saudi and Western (North American & UK) versions of the PSI-SF, Brief COPE, SPS, FSS, the HADS and the SDQ. Therefore, the general purpose is to assess the level of stress, coping, social support, and mental health in mothers of TD children and mothers of ID children.

The reliability, internal consistency, factor scores and inter-scale correlations for the Saudi scales were compared with previously reported data from north American/UK studies. To achieve the goal of this study, the following specific research questions are identified and addressed:

1. Are the validity and reliability of the scales (PSI-SF, Brief COPE, SPS, FSS, HADS & SDQ) maintained in the Arabic versions?
2. Are there differences in the mean scores of all the measures, between Saudi and western (north-American/UK) normative samples?
3. Are there any differences between Saudi and western (north-American/UK) families of children with ID?
4. Are there differences in coping, social support, stress and mental health (anxiety and depression) between Saudi mothers of TD children and mothers of children with ID?

5. What are the factor structures of the Arabic scales?

## 9.3 Methods:

### 9.3.1. Participants:

About 1600 questionnaires were distributed to mothers of TD and disabled children in Makkah and Jeddah. They were recruited via schools, playgroups, kindergartens, and intellectual disability institutes. One thousand and seventeen mothers returned their questionnaires. (504 mothers of TD and 513 of ID children) (Tables 22 and 23)

### 9.3.1.1.The Typically Developing group (TD):

The sample was selected from the population of children aged between two and a half and twelve years living in Makkah and Jeddah, the two main cities in the Makkah area, in the west of Saudi Arabia (see Chapter 5). A total of 800 questionnaires were randomly distributed to mothers of TD children via kindergartens and elementary schools. Moreover, each mother was asked to recommend a friend or relative to participate in the study. Mothers were asked to complete the questionnaires at schools if they wanted or if they preferred to complete them at home and then send them back to the schools. Illiterate mothers received help either from the researcher or from the school's social worker. Mothers were asked to complete the whole questionnaire and to make sure that they did not omit any item. 504 (63%) of the participants returned their questionnaires, 486 (96.42%) of the mothers fully completed the questionnaires or just omitted some of the questionnaires' items, whereas, 18 (3.57%) of the mothers only completed the demographic data scales and did not respond to the other scales. They either omitted most of the items or did not answer them at all.

Table 22 is about the characteristics of the study sample. These data shows that the sample was representative of the characteristics of Saudi families living in urban areas in west Saudi Arabia (Makkah and Jeddah).

Table 22: Characteristics of the TD sample

| | (%) and (M) |
|---|---|
| Gender of the child (males%) | 49% |
| Birth order (%) | 41% first child- 33% middle child- 26% last child |
| Kinship of parents (%) | 37% relatives- 36% not relatives |
| Mothers' marital status (%) | 93% married- 5% divorced |
| Polygamy (%) | 93% one-wife family- 7% two-wife family |
| Family structure (%) | 37% extended family, 63% nuclear family |
| Mother's job (%) | 65% housewives, 33% working women |
| Family's income (%) | 15% low, 14% mid-low, 45% medium, 17% mid-high, 4% high, 3% very high |
| Number of children (M) | M= 3.4, SD=2.13 (range: 1 to 12) |
| Age of the child (M) in years | M=6.59, SD=2.66 (range:2 to 12) |
| Mother's age (M) | M=32.50, SD=6.88 (range: 17.5 to 50) |
| Father's age (M) | M=38.61, SD=8.63 (range: 25 to 75) |
| Mothers' education (M) in years | M=12.69, SD=4.10 |
| Father's education (M) | M=13.75, SD=4.06 |

### 9.3.1.2. The Intellectually Disabled group (ID):

A sample of mothers of children between 2.6- 12 years old from all schools and institutes was recruited. About 850 questionnaires were distributed. Five hundred and thirteen mothers of ID children from Makkah and Jeddah returned the questionnaires. All of these children live with their natural families. All children enrolled in these schools have mild to moderate Intellectual Disability (IQ=35-70) with or without physical disabilities, such as children with mental retardation, Down's Syndrome, cerebral palsy, autism, hydrocephalus, and ID with unknown aetiology. Although we asked the schools to distribute the questionnaires to mothers of children aged between 2.6 and 12, we were told that some mothers of children above that age offered to participate in this study. Their participation was appreciated and will be included in this chapter and in Chapter 10. However, participating mothers of children aged 13 (58 mothers), 14 (32 mothers) and 16 (2 mothers) will be excluded from any analyses comparing the TD and the disabled groups in this chapter.

The IQ level of all the ID children was recorded in their school files. These tests have been done either by school doctors or social workers. All of the governmental and the non-governmental schools use the Stanford-Binet intelligence scale. According to schools' acceptance terms only children with mild to moderate IQ are admitted. However, there were 27 mothers of children with borderline IQ (IQ=75) in the returned questionnaires. They will be included in this chapter and in Chapter 10 as well.

Table (23) presents the characteristics of the sample of families of children with ID living in urban areas in west Saudi Arabia (Makkah and Jeddah).

Table 23: Characteristics of the ID sample

| | *(%) and (M)* |
|---|---|
| Gender of the child (males%) | 61% Male |
| Type of disability | 21% Down's syndrome, 9% Cerebral palsy, 4% hydrocephalus, 4% autism, 11% other disabilities & 47% unknown aetiology |
| Other disability | 20% yes & 75% no |
| Disability in other family member | 20% yes & 77% no |
| Birth order (%) | 21% First child-54 % Middle child- 21% Last child |
| Kinship of parents (%) | 49% Relatives- 47% Not relatives |
| Mothers' marital status (% | 86% Married & 5% divorced |
| Polygamy (%) | 81% one-wife family- 14% Two-wife family |
| Family structure (%) | 29% Extended family& 68% Nuclear family |
| Mother's job (%) | 84% House Wives, 9% working women |
| Family's income (%) | 28% Low, 34% Mid-Low, 18% Middle, 4% Mid-High, and 3% High |
| IQ | M= 59.95, SD= 9.30 (range: 35-75) |
| Number of children (M) | M=5.61, SD= 2.84 (range: 1 to 14) |
| Age of the child (M) in years | M=9.54, SD=2.91 (range: 2.6 to16) |
| Mother's age (M) | M=38.58, SD=7.27 (range: 23 to 65) |
| Father's age (M) | M=47.21, SD=10.30 (range: 28 to 95) |
| Mothers' education (M) in years | M= 7.06, SD= 5.25 |
| Father's education (M) | M=8.52, SD= 5.08 |

### 9.3.2. Data collection:

Letters inviting participation were sent to mothers via schools, kindergartens and playgroups and questionnaires were distributed to mothers who consented. Mothers who were illiterate or had a very low education level were invited to complete the questionnaires with help from either the researcher or the social workers in the schools. All the questionnaires were returned to the schools when completed. The cover of the questionnaires included a letter that briefly explained the purpose of the study, encouraging the mothers' participation and assuring them of the confidentiality of the study.

### 9.3.3. Missing data:

Some of the participants in the TD group filled in only the demographic data and did not respond to any of the other questions. A Mann-Whitney test for independent samples was used in order to find any differences between the mothers of TD children who completed all the questionnaires (486 participants, 96.4%) and those who did not (18 participants, 3.5%). Results revealed no significant differences between the two groups for all of the demographic data except of the child age ($p<.05$). Mothers who completed all questionnaires tend to have older children ($M=6.64$, $SD=2.67$) than those who only completed the demographic data ($M= 5.27$, $SD= 1.96$)

## 9.4 Procedures:

### 9.4.1. Instruments:

The same instruments that have been used before in the previous studies (chapters 7 and 8) were used here. Moreover, the SDQ (Goodman, 1997) was added to the scales used in this study. Hence, the sum of all the instruments that have been used in this study is seven questionnaires: the PSI-SF (Abidin, 1995), the Brief COPE Scale (Carver, 1997), the SPS (Russel & Cutrona, 1984), the FSS (Dunst, Carlo, Trivette & Deborah, 1993), the HADS (Zigmond & Snaith, 1983), the SDQ (Goodman, 1997) and the demographic data scale.

It is worth mentioning that the SDQ questionnaire had already been translated and its validity and reliability tested with Arabic norms (Thabit, 2000). It was not included in Chapters 7 and 8. In this chapter it has been only tested with mothers with ID children. For more information on the SDQ in detail see Chapter 6 for the relevant psychometric data from previous studies.

## 9.5. RESULTS:

### 9.5.1. Answering question 1:

The first introductory step in preparing for the main study was to retest the reliability of all the scales. In order to test this, correlations and internal consistency were tested.

Firstly, we produced descriptive statistics of the scales to compare them. Then the correlation between all the scales was found. After that, the correlation between the subscales of each scale were established separately.

In order to test the correlations of all the questionnaires for each group independently, independent tests for the TD and the ID groups were tested. Table 24 shows very high negative and positive correlation between all questionnaires. For the TD group, correlation was significant at the 0.01 level (2-tailed) for all scales. For the ID group moderately significant positive and negative correlation was shown between all scales.

Table 24: Correlations between all questionnaires

| | TD | | | | ID | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 2 | 3 | 4 | 5 | 2 | 3 | 4 | 5 | 6 |
| 1. PSI-SF | -.65** | -.73** | -.54** | .69** | -.17** | -.28** | -.43** | .70** | .78** |
| 2. Brief COPE | 1.00 | .70** | .50** | -.46** | 1.00 | .14* | .20** | -.21** | -.23** |
| 3. SPS | | 1.00 | .45** | -.40** | | 1.00 | .23** | -.19** | -.26** |
| 4. FSS | | | 1.00 | -.40** | | | 1.00 | -.29** | -.29** |
| 5. HADS | | | | 1.00 | | | | 1.00 | .61** |
| 6. SDQ | | | | | | | | | 1.00 |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level

Table 25 presents the means of the PSI-SF subscales and Table 26 shows the correlations of PSI-SF subscales for the TD and ID groups. The results revealed that there were high positive correlations between the three subscales for both samples. Correlation was significant at the level 0.01 (2-tailed) for all subscales.

Table 25: PSI-SF subscales descriptive statistics

| | TD | | | *ID* | | |
|---|---|---|---|---|---|---|
| | Mean | SD | N | *N* | *Mean* | *SD* |
| 1.PD | 31.15 | 10.70 | 471 | 358 | 35.30 | 9.33 |
| 2. P-CDI | 25.71 | 10.01 | 476 | 362 | 35.43 | 8.40 |
| 3. DC | 31.71 | 11.20 | 481 | 361 | 38.99 | 9.13 |

Table 26: PSI-SF subscales correlation

| | TD | | *ID* | |
|---|---|---|---|---|
| | P-CDI | DC | *P-CDI* | *DC* |
| 1. PD | .74** | .76** | .59** | .57** |
| 2. P-CDI | 1.00 | .76** | 1.00 | .65** |
| 3. DC | | 1.00 | | 1.00 |

**Correlation is sign. at a 0.01 level

Table 27 presents the means of the Brief COPE's fifteen subscales, whilst Table 28 shows that there is a significant positive correlation between all Brief COPE sub-scales for the TD group. Correlation was significant at the 0.01 and 0.05 level (2-tailed) for all subscales except for items 4, and 7. The substance-use subscale (4) did not correlate with the active cope, positive reframing, acceptance, religion and belief subscales. The behavioural disengagement (7) only did not correlate with the religion subscale. On the other hand, the ID group showed a significant correlation except for religion, which did not correlate significantly with self-distraction, denial, emotional support, behavioural disengagement and humour. Belief did not correlate with substance use and denial. And positive reframing failed to correlate only with substance use (Table 28).

Table 27: Descriptive statistics of Brief COPE subscales

| | TD | | | *ID* | | |
|---|---|---|---|---|---|---|
| | Mean | SD | N | *N* | *Mean* | *SD* |
| 1. Self distraction | 5.41 | 1.87 | 485 | 364 | 4.84 | 1.80 |
| 2. Active coping | 6.08 | 1.74 | 485 | 371 | 5.90 | 1.63 |
| 3. Denial | 4.29 | 1.95 | 485 | 367 | 3.74 | 1.79 |
| 4. Substance use | 2.79 | 1.55 | 485 | 370 | 2.73 | 1.55 |
| 5. Emotional support | 5.69 | 1.82 | 485 | 369 | 5.08 | 1.91 |
| 6. Instrumental support | 5.79 | 1.88 | 485 | 365 | 5.42 | 1.78 |
| 7. Behavioural disengagement | 4.33 | 2.06 | 485 | 364 | 3.81 | 1.90 |
| 8. Venting | 5.44 | 1.86 | 485 | 365 | 4.73 | 1.79 |
| 9. Positive reframing | 6.09 | 1.73 | 485 | 383 | 5.75 | 2.03 |
| 10. Planning | 6.19 | 1.66 | 485 | 375 | 6.17 | 1.65 |
| 11. Humour | 4.68 | 2.13 | 485 | 406 | 3.62 | 1.65 |
| 12. Acceptance | 6.19 | 1.62 | 485 | 364 | 5.93 | 1.69 |
| 13. Religion | 7.32 | 1.27 | 485 | 367 | 7.41 | 1.27 |
| 14. Self-blame | 5.81 | 1.88 | 485 | 363 | 4.91 | 1.92 |
| 15. Belief | 7.14 | 1.39 | 485 | 367 | 7.46 | 1.28 |

Table 28: Correlation between Brief COPE subscales

| | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| TD group | | | | | | | | | | | | | | |
| 1. Self-distraction | .36** | .48** | .15* | .43** | .39** | .46** | .45** | .37** | .33** | .50** | .35** | .19** | .34** | .17** |
| 2. Active cope | 1.00 | .31** | **.05** | .46** | .40** | .16** | .50** | .67** | .54 | .25** | .56** | .37** | .40** | .32** |
| 3. Denial | | 1.00 | .30** | .38** | .36** | .60** | .40** | .36** | .34 | .48** | .31** | .18** | .45** | .22** |
| 4. Substance use | | | 1.00 | .14* | .13* | .36** | .12* | **.07** | .10 | .16** | **.07** | **-.01** | .15* | **.01** |
| 5. Emotional support | | | | 1.00 | .66** | .38** | .55** | .48** | .47 | .45** | .57** | .31** | .46** | .23** |
| 6. Instrumental support | | | | | 1.00 | .40** | .50** | .47** | .46 | .39** | .48** | .32** | .45** | .26** |
| 7.Behavioral - disengagement | | | | | | 1.00 | .38** | .20** | .29 | .41** | .28** | .11* | .34** | **.07** |
| 8. Venting | | | | | | | 1.00 | .54** | .50 | .38** | .54** | .26** | .48** | .24** |
| 9. Positive reframing | | | | | | | | 1.00 | .66 | .37** | .62** | .35** | .49** | .33** |
| 10. Planning | | | | | | | | | 1.00 | .34** | .58** | .39** | .46** | .35** |
| 11. Humour | | | | | | | | | | 1.00 | .34** | .15* | .44** | .18** |
| 12. Acceptance | | | | | | | | | | | 1.00 | .37** | .48** | .27** |
| 13. Religion | | | | | | | | | | | | 1.00 | .19** | .50** |
| 14. Self bame | | | | | | | | | | | | | 1.00 | .18** |
| 15. Belief | | | | | | | | | | | | | | 1.00 |
| ID group | | | | | | | | | | | | | | |
| 1. Self-Distraction | .25** | .32** | .26** | .31** | .20** | .37** | .38** | .24** | .28** | .40** | .32** | **.06** | .35** | .13* |
| 2. Active cope | 1.00 | .14* | .14* | .29** | .23** | .23** | .29** | .33** | .45** | .23** | .35** | .25** | .30** | .12* |
| 3. Denial | | 1.00 | .37** | .16** | .16** | .50** | .35** | .16** | .21** | .36** | .14* | **.05** | .37** | **.07** |
| 4. Substance use | | | 1.00 | .16** | .22** | .49** | .30** | **.09** | .13* | .32** | .14* | **.02** | .22** | **.01** |
| 5. Emotional support | | | | 1.00 | .49** | .23** | .27** | .28** | .31** | .32** | .37** | .23** | .22** | .23** |
| 6. Instrumental support | | | | | .100 | .23** | .25** | .23** | .32** | .20** | .34** | .27** | .24** | .21** |
| 7.Behavioral-disengagement | | | | | | 1.00 | .40** | .15* | .22** | .34** | .24** | **.05** | .40** | .10* |
| 8. Venting | | | | | | | 1.00 | .27** | .39** | .41** | .43** | .14* | .46** | .14* |
| 9. Positive reframing | | | | | | | | 1.00 | .38** | .20** | .39** | .25** | .27** | .16** |
| 10. Planning | | | | | | | | | 1.00 | .23** | .51** | .37** | .42** | .25** |
| 11. Humour | | | | | | | | | | 1.00 | .25** | **.03** | .41** | .10* |
| 12. Acceptance | | | | | | | | | | | 1.00 | .30** | .28** | .29** |
| 13. Religion | | | | | | | | | | | | 1.00 | .15* | .68** |
| 14. Self-blame | | | | | | | | | | | | | 1.00 | .11* |
| 15. Belief | | | | | | | | | | | | | | 1.00 |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level & Insignificant correlation was shown in bold type

Table 29 shows the SPS subscales' descriptive statistics and Table 30 shows significant positive correlation between all SPS sub-scales. Correlation was significant at the 0.01 level (2-tailed) for both groups.

Table 29: Descriptive statistics of SPS Subscales

| | TD | | | *ID* | | |
|---|---|---|---|---|---|---|
| | Mean | SD | N | *N* | *Mean* | *SD* |
| 1.Guidance | 13.19 | 2.65 | 482 | 344 | 12.24 | 2.22 |
| 2.Reassurance of worth | 12.93 | 2.58 | 482 | 341 | 12.17 | 2.24 |
| 3. Social integration | 12.70 | 2.60 | 482 | 331 | 11.71 | 2.16 |
| 4. Attachment | 12.73 | 2.68 | 484 | 346 | 12.07 | 2.04 |
| 5. Nurturance | 12.86 | 2.57 | 480 | 349 | 12.06 | 2.14 |
| 6. Reliable alliance | 12.95 | 2.63 | 483 | 347 | 12.21 | 2.25 |

Table 30: Correlation between SPS subscales

|  | TD |  |  |  |  |
|---|---|---|---|---|---|
|  | 2 | 3 | 4 | 5 | 6 |
| 1. Guidance | .71** | .73** | .75** | .61** | .75** |
| 2. Reassurance of worth | 1.00 | .73** | 70** | .70** | .71** |
| 3. Social integration |  | 1.00 | .69** | .73** | .73** |
| 4. Attachment |  |  | 1.00 | .56** | .66** |
| 5. Nurturance |  |  |  | 1.00 | .70** |
|  | ID |  |  |  |  |
| 1. Guidance | .44** | .42** | .47** | .32** | .60** |
| 2. Reassurance of worth | 1.00 | .47** | .53** | .35** | .46** |
| 3. Social integration |  | 1.00 | .43** | .47** | .48** |
| 4. Attachment |  |  | 1.00 | .36** | .38** |
| 5. Nurturance |  |  |  | 1.00 | .38** |

**Correlation is sign. at a 0.01 level.

Regarding the FSS, descriptive statistics of all five sub-scales were found in Table 31. In addition, Table 32 shows a high level of significance between FSS sub-scales. Correlation was significant at the 0.01 level (2-tailed) for both TD and ID groups.

For the FSS, all of the five sub-scales showed moderate correlation level (from .72 to .77), which was lower for the two or three items sub-scales and higher for the four and five items sub-scales (Table 32).

Table 31: Descriptive statistics of FSS subscales

|  | TD |  |  | *ID* |  |  |
|---|---|---|---|---|---|---|
| Sub-scales | Mean | SD | N | *N* | *Mean* | *SD* |
| 1. Husband | 8.39 | 3.88 | 478 | 342 | 6.68 | 3.82 |
| 2. Informal kinship | 10.21 | 5.35 | 476 | 341 | 8.98 | 5.78 |
| 3. Formal kinship | 5.80 | 2.93 | 481 | 350 | 4.60 | 3.00 |
| 4. Social organisations | 5.50 | 4.15 | 474 | 339 | 4.89 | 4.24 |
| 5. Professional services | 4.65 | 4.02 | 475 | 342 | 5.15 | 5.04 |

Table 32: FSS subscales correlation

|  | TD |  |  |  |
|---|---|---|---|---|
| Sub-scales | 2 | 3 | 4 | 5 |
| 1. Husband | .51** | .68** | .32** | .38** |
| 2. Informal kinship | 1.00 | .46** | .66** | .59** |
| 3. Formal kinship |  | 1.00 | .36** | .35** |
| 4. Social organisations |  |  | 1.00 | .70** |
|  | ID |  |  |  |
| 1. Husband | .61** | .56** | .53** | .37** |
| 2. Informal kinship | 1.00 | .49** | .70** | .54** |
| 3. Formal kinship |  | 1.00 | .49** | .32** |
| 4. Social organisations |  |  | 1.00 | .61** |

**Correlation is sign. at a 0.01 level.

In order to examine the HADS questionnaire, descriptive statistics of the anxiety and depression sub-scales were given in Table 33. Moreover, Table 34 presents a highly significant correlation between the two sub-scales (P<0.01) for both groups.

Table 33: Descriptive statistic of the HADS subscales

| Sub-scales | TD | | | *ID* | | |
|---|---|---|---|---|---|---|
| | Mean | SD | N | *Mean* | *SD* | *N* |
| Anxiety | 8.16 | 4.41 | 486 | 8.86 | 5.51 | 414 |
| Depression | 3.61 | 2.96 | 486 | 5.92 | 4.41 | 413 |

Table 34: Correlation between HADS subscales

| Sub-scales | TD group | | *ID group* | |
|---|---|---|---|---|
| | 1 | 2 | *1* | 2 |
| 1. Anxiety | 1.00 | .64** | 1.00 | .63** |
| 2. Depression | | 1.00 | | 1.00 |

**Correlation is sign. at a 0.01 level.

Regarding the SDQ, Table 35 presents the descriptive statistics of all the five subscales only for the intellectually disabled group. Results showed that the emotional symptoms, the conduct problems and the hyperactivity means were at the borderline level. However, the Peer Problems and the prosocial subscales means were at the abnormal level.

Table 35: Descriptive statistics of the SDQ

| | N | Minimum | Maximum | M | SD |
|---|---|---|---|---|---|
| 1.Emotional symptom scale | 490 | .00 | 10.00 | 4.27 | 2.74 |
| 2.Conduct problems scale | 488 | .00 | 10.00 | 2.93 | 2.22 |
| 3.Hyperactivity scale | 486 | .00 | 10.00 | 6.34 | 3.12 |
| 4.Peer problem scale | 487 | .00 | 10.00 | 5.31 | 3.01 |
| 5.Prosocial scale | 479 | .00 | 10.00 | 3.98 | 1.86 |

Table 36 presents the correlation between all the SDQ sub-scales for the ID group. Results showed that all the first four subscales are highly correlated (P< .001) whereas the prosocial subscale did not correlate significantly with any of the other sub-scales.

Table 36: Correlation between SDQ subscales

| | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| 1.Emotional symptom scale | .64** | .64** | .70** | -.00 |
| 2.Conduct problems scale | 1.00 | .53** | .66** | -.07 |
| 3.Hyperactivity scale | | 1.00 | .70** | .05 |
| 4.Peer problem scale | | | 1.00 | .04 |
| 5.Prosocoial scale | | | | 1.00 |

**Correlation is sign. at a 0.01 level.

## 2. Internal consistency:

In order to retest the validity of all scales, internal consistency was tested using Cronbach's alpha, which has been reported for both groups separately (TD and ID children) in order to test the internal consistency of complete scales and of the subscales of all questionnaires. Table 37 reveals a high level of alpha for all questionnaires: for the TD group alpha level from .89 to .96 and .83 to .93 for the ID group. Combining the whole sample, Table 37 reveals a high alpha level for all scales (from .89 to .95). Alpha levels as reported in the literature were presented in the last column of the table. Internal consistency seemed to be similar to what has been found before in most scales, PSI-SF (Abidin, 1995), SPS (Russel & Cutrona, 1984), FSS (Dunst, Carlo, Trivette & Deborah, 1993), and HADS (Zigmond & Snaith, 1983). However, for the Brief COPE (Carver, 1997) and the SDQ (Goodman, 1997) there were large differences in the results with a higher level of alpha reported in this study than in Carver's (1997) and Emerson's (2002) and even in Beck's (2002). The alpha level in the present study was found to be above .80 for the total difficulties score in the SDQ.

Table 37: Internal consistency for all scales

| Scale | TD group | ID group | Both samples | Published studies |
|---|---|---|---|---|
| PSI-SF | .96 | .92 | .95 | .9 |
| Brief COPE | .92 | .88 | .91 | .67 |
| SPS | .94 | .83 | .91 | .91 |
| FSS | .89 | .89 | .89 | .85 |
| HADS | .92 | .93 | .93 | .94 |
| SDQ | - | .93 | .93 | .80 |

In order to test the reliability of all of the questionnaires' sub-scales, Cronbach's alpha was tested for each sub-scale separately. For the PSI-SF sub-scales, Table 38 shows an alpha level of PSI-SF subscales ranging between .89 to .92. For the ID group an alpha level ranged between .81 to .86, which is considered high. For all participants combined, Table 38 reveals a high alpha level for all three sub-scales (from .88 to .90). Internal consistency for the three sub-scales in the last column has been presented in the literature: Abidin (1995) revealed a nearly similar level of alpha for all sub-scales with a slightly higher alpha level in the DC sub-scale in this study.

Table 38: Internal consistency of PSI-SF subscales

| Sub-scales | TD group | ID group | Both samples | Published studies |
|---|---|---|---|---|
| Parental distress (PD) | .89 | .85 | .88 | .87 |
| Parent-child dysfunctional interaction (P-CDI) | .90 | .81 | .88 | .80 |
| Difficult child | .92 | .86 | .90 | .85 |

For the Brief COPE sub-scales, the internal consistency for the TD varied from .55 to .94. All of the sub-scales exceeded.60 or more except for the venting and acceptance subscales, where they exceeded .55 and .59 in the TD group and.47 and .47 for the ID group. When testing internal consistency for the whole sample together, alpha was greater than .60 for all sub-scales, which is considered acceptable. However, only the venting and acceptance sub-scales showed a low alpha level, 0.53 for venting and 0.54 for acceptance (Table 39). It is worth mentioning that these two sub-scales also exceeded a low level of alpha in Carver's study (acceptance= .57 and venting= .50) (Carver, 1997). The rest of the sub-scales have an alpha level similar to what is reported in this study (Table 39).

Table 39: Internal consistency of Brief COPE Subscales

| Sub-Scales | TD group | ID group | Both samples | Published studies |
|---|---|---|---|---|
| 1. Self distraction | .65 | .59 | .61 | .71 |
| 2. Active coping | .65 | .63 | .65 | .68 |
| 3. Denial | .79 | .69 | .75 | .54 |
| 4. Substance use | .80 | .83 | .81 | .90 |
| 5. Emotional support | .65 | .65 | .66 | .71 |
| 6. Instrumental support | .74 | .63 | .71 | .64 |
| 7. Behavioural disengagement | .81 | .74 | .79 | .65 |
| 8. Venting | .55 | .47 | .53 | .50 |
| 9. Positive reframing | .64 | .59 | .62 | .64 |
| 10. Planning | .63 | .61 | .61 | .73 |
| 11. Humour | .80 | .59 | 74 | .73 |
| 12. Acceptance | .59 | .47 | .54 | .57 |
| 13. Religion | .79 | .80 | .80 | .82 |
| 14. Self blame | .76 | .62 | .71 | .69 |
| 15. Belief | .94 | .73 | .84 | ---- |

For the SPS, Table 40 reveals adequate levels of alpha for all the SPS subscales. Alpha was between .69 and .73 for the TD group, and between .48 and .67 for the ID group. All of the subscales exceeded an alpha level of .50 except for the attachment subscales, which was the lowest of all subscales (.48). When the internal consistency for the whole sample was examined, all the sub-scales exceeded alpha levels (from .65 to 71) (Table 40), which was low but accepted by many researchers (e.g. Carver, 1997). Table 40 also shows the internal consistency results of Cutrona, Daniel & Russel (1987), which was an almost similar alpha level for most of the sub-scales however the nurturance and attachment sub-scales showed a higher level of alpha than in the literature.

Table 40: Internal consistency of SPS subscales

| Sub-scales | TD group | ID group | Both samples | Published studies |
|---|---|---|---|---|
| 1. Guidance | .73 | .54 | .67 | .76 |
| 2. Reassurance of worth | .73 | .58 | .67 | .2.0 |
| 3. Social integration | .72 | .54 | .66 | .67 |
| 4. Attachment | .69 | .48 | .62 | .74 |
| 5. Nurturance | .73 | .67 | .71 | .91 |
| 6. Reliable alliance | .72 | .51 | .65 | .65 |

Table 41 shows a moderate level of alpha for all sub-scales from .73 to .76 for the TD and between .67 and .80 for the ID group, and between .72 and .77 for the whole sample.

Table 41: Internal consistency of FSS subscales

| Sub-scales | TD group | ID group | Both samples |
|---|---|---|---|
| 1. Husband | .75 | .67 | .72 |
| 2. Informal kinship | .76 | .70 | .74 |
| 3. Formal kinship | .73 | .69 | .72 |
| 4. Social organization | .73 | .73 | .73 |
| 5. Professional service | .73 | .80 | .77 |

According to the HADS internal consistency, the results shown in Table 42 reveal a high alpha level for both HADS sub-scales: .88 and .90 for the TD group and.89 and .93 for the ID group. When testing the alpha level for the whole sample the results showed .92 for anxiety and .89 for depression, which are slightly higher than those reported in the literature (Hastings & Brown, 2002).

Table 42: Internal consistency of HADS subscales

| Sub-scales | T.D group Alpha | *ID group Alpha* | Both samples | Published studies |
|---|---|---|---|---|
| Anxiety | .90 | .93 | .92 | .86 |
| Depression | .88 | .89 | .89 | .86 |

Finally, the internal consistency for the five SDQ sub-scales were between .81 and .95 which is considered a high level of alpha. There were differences between these results and what have been reported in the literature (Beck, 2002) with higher levels of alpha for all of the sub-scales in this study (Table 43).

Table 43: Internal consistency for the SDQ

| Sub-scale | N of cases | N of items | Alpha | Published studies |
|---|---|---|---|---|
| 1. Emotional symptom scale | 490 | 5 | .90 | .56 |
| 2. Conduct problem | 488 | 5 | .81 | .77 |
| 3. Hyperactivity | 486 | 5 | .95 | .77 |
| 4. Peer problems | 487 | 5 | .95 | .60 |
| 5. Prosocial scale | 479 | 5 | .86 | ..78 |

### 9.5.3. Answering question 2:

### Differences between Saudi and the western (USA/UK) norms:

In this step we compared the means and standard deviations between the Saudi and USA/UK (Western) samples. Table 44 shows the differences between the results of all questionnaires. According to Abidin (1995) the mean level of stress for the Saudi mothers was high (more than 85). When this result was compared with the western sample, the Saudi sample revealed more stress than the western sample (Reitman, Currier, & Stickle, 2002). For the Brief COPE scale, the mean results of the Saudi sample were higher than those of the western (Perczek, Carver & Price, 2000). For the SPS, Saudi mothers received significantly less support than the American sample (Cutrona & Russell, 1987), whereas in another study (Cutrona, 1984) the mothers' mean total score was lower than the Saudi sample's (M=74.19, SD=7.28). The FSS results have also shown less support received by Saudi mothers when compared to western mothers (Dunst et al., 1993). Finally, the HADS results have shown a mild level of mental health problems in British mothers while Saudi mothers have a moderate level of mental health problems (Crawford, Henry, Crombie & Taylor, 2001).

An explanation for the differences between the means in Saudi and western samples might be that the samples were not 100% comparable. For all questionnaires, mothers were recruited in the Saudi study, whereas with the Brief COPE study 148 undergraduate students (101 females- 47 males) ranging in age from 18 to 37 (M=19.42) were recruited. With the SPS 1792 participants were recruited: 1183 students, 303 public school teachers, 306 nurses (Cutrona, Russell, 1987), or a sample (N=85) of eight-weeks postpartum women ranging in age from 18 to 35 (M=26) (Cutrona, 1984). For the FSS, 224 of both mothers and fathers were recruited (174 mothers, and 50 fathers).

Table 44: Descriptive statistics of western and Saudi sample (TD)

| | Western samples | | Saudi sample | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| PSI-SF | 73.44 | 25.56 | 88.22 | 29.41 |
| Brief COPE | 74.38 | 25.93 | 83.98 | 16.68 |
| Self-distraction | 5.41 | 1.73 | 5.41 | 1.86 |
| Active coping | 5.95 | 1.72 | 6.10 | 1.70 |
| Denial | 3.83 | 1.98 | 4.32 | 1.93 |
| Substance use | 2.76 | 1.52 | 2.80 | 1.54 |
| Use of emotional support | 5.97 | 1.92 | 5.71 | 1.79 |
| Use of instrumental support | 5.97 | 1.92 | 5.82 | 1.84 |
| Behavioural disengagement | 3.29 | 1.44 | 4.38 | 2.03 |
| Venting | 5.21 | 1.70 | 5.48 | 1.82 |
| Positive reframing | 5.41 | 1.77 | 6.10 | 1.72 |
| Planning | 6.00 | 1.66 | 6.19 | 1.66 |
| Humour | 3.84 | 1.90 | 4.70 | 2.12 |
| Acceptance | 6.24 | 1.56 | 6.21 | 1.61 |
| Religion | 4.94 | 2.21 | 7.32 | 1.27 |
| Self-blame | - | - | 5.83 | 1.86 |
| Belief | - | - | 7.20 | 1.24 |
| SPS | 82.45/ 74.19 | 9.89/ 7.28 | 77.17 | 13.84 |
| FSS | 48.45 | 10.73 | 34.52 | 16.01 |
| HADS | 9.82 | 5.98 | 11.77 | 6.69 |
| Anxiety | 6.14 | 3.76 | 8.16 | 4.41 |
| Depression | 3.68 | 3.07 | 3.61 | 2.96 |

Table 45 shows the differences between Saudi and western means demonstrated by the use of one sample t-test. Results revealed that the PSI-SF, Brief COPE, SPS, FSS and the HADS showed significant differences of mean between Saudi and western sample p< .001. A test of the differences in levels of anxiety and depression showed significant differences between the two groups in anxiety p<.001 with a higher anxiety level shown by Saudi participants, whereas, western participants showed an insignificantly higher level of depression: P=-6.88, which means no difference between the Saudi and western samples in depression level. Regarding the coping strategies, there were significant differences between the two samples in active coping, denial, emotional support, behavioural disengagement, venting, positive reframing, planning, humour and religion. The Saudi sample showed a significantly higher level of use of all these strategies, except for emotional support, where the western sample was higher. In addition, no differences were evident between the two samples with regard to self-distraction, substance use, instrumental support and acceptance. It is worth mentioning that the substance use strategy was used differently by the Saudi sample. It was called alcohol/drug use in the literature, while it was called a medicine use (e.g. tranquillisers and sleeping pills) in the Saudi sample. Hence, there was no sense in comparing these two items. Emotional support and instrumental support were combined into social support in the Perczek et al. study (2000), however, when we compared it with this study the same mean was inferred to compare emotional and instrumental support. Finally, self-blame was not included in Perczek, Carver & Price (2000), so results could not be compared between the two groups.

Table 45: Mean differences between Western and Saudi (TD)

| Questionnaire | t | df | Sig (2-tailed) |
|---|---|---|---|
| PSI-SF | 10.79 | 460 | .00 |
| Brief COPE | 12.37 | 482 | .00 |
| Self-distraction | .06 | .348 | .95 |
| Active coping | 1.98 | 482 | .04 |
| Denial | 5.66 | 482 | .00 |
| Substance use | .59 | 483 | .55 |
| Use of emotional support | -3.15 | 482 | .00 |
| Use of instrumental support | -1.74 | 481 | .08 |
| Behavioural disengagement | 11.90 | 480 | .00 |
| Venting | 3.26 | 481 | .00 |
| Positive reframing | 8.83 | 481 | .00 |
| Planning | 2.59 | 484 | .01 |
| Humour | 8.91 | 481 | .00 |
| Acceptance | -.38 | 481 | .70 |
| Religion | 18.65 | 484 | .00 |
| SPS (support satisfaction) | -7.70 (5.13) | 462 (467) | .00/.00 |
| FSS | -18.80 | 462 | .00 |
| HADS | 6.39 | 485 | .00 |
| Anxiety | 10.08 | 485 | .00 |
| Depression | -.51 | 485 | .60 |

### 9.5.4. Answering question 3:

### Differences in mean and standard deviation between Saudi and the western (American/UK) samples of mothers of ID children:

Mean and standard deviation of Saudi and western studies of mothers of ID children were established in order to answer the last question. Table 46 shows that Saudi women suffered a higher level of stress and mental health problems than their peers in the west (Hastings & Brown, 2002; Tomanic, Harris & Hawkins, 2004). That these mothers received less support than their western peers is reported in the literature (M=23.3- 24.3, SD=7.3) (Dyson, 1997; Krauss, 1993). Moreover, their children were remarkably higher in BD than those in western culture (mean ranged between 12.3 and 16.81, SD=6.23 to 6.97) (Beck, 2002; Madden, Hastings & Hoff, 2002; Pit-ten Cate, 2003). For all coping strategies, except acceptance, Saudi mothers showed a higher level of use of coping strategies than British mothers (Pit-ten-Cate, 2003).

Table 46: Descriptive statistics of western and Saudi mothers of ID children

| | Western samples | | Saudi sample | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| PSI-SF | 97.35 | 20.16 | 109.93 | 23.03 |
| Brief COPE | 49.13 | 13.11 | 77.84 | 14.64 |
| Self-distraction | 3.61 | 1.47 | 4.90 | 1.77 |
| Active coping | 4.75 | 1.88 | 5.89 | 1.65 |
| Denial | 2.51 | 1.07 | 3.81 | 1.79 |
| Substance use | 2.48 | 1.16 | 2.76 | 1.57 |
| Use of emotional support | 4.17 | .1.67 | 5.15 | 1.90 |
| Use of instrumental support | 4.54 | 1.76 | 5.50 | 1.81 |
| Behavioural disengagement | 2.48 | .92 | 3.85 | 1.94 |
| Venting | 3.46 | 1.56 | 4.74 | 1.78 |
| Positive reframing | 4.36 | 1.71 | 5.76 | 1.98 |
| Planning | 4.72 | 1.84 | 6.12 | 1.67 |
| Humour | 3.04 | 1.48 | 3.68 | 1.71 |
| Acceptance | 6.11 | 1.87 | 5.93 | 1.69 |
| Religion | - | - | 7.46 | 1.23 |
| Self-blame | 4.10 | 1.88 | 4.95 | 1.92 |
| Belief | - | - | 7.46 | 1.27 |
| SPS | 90.15 | - | 72.75 | 9.77 |
| FSS | 23.3 | 7.3 | 30.50 | 17.55 |
| HADS | 13.15 | 8.49 | 15.07 | 8.23 |
| Anxiety | 7.92 | 4.44 | 8.89 | 4.98 |
| Depression | 5.23 | 4.06 | 5.95 | 3.94 |
| SDQ | 16.81 | 6.23 | 22.96 | 9.96 |

In order to find whether these differences in means between this study's results and those reported in the literature were significant, t-test was used and revealed that there were significant differences between all of these questionnaires. Saudi mothers of children with ID were more stressed, had more mental health problems, received less support and reported more child behavioural problems than western mothers. In addition, mothers in this study used higher levels of coping strategies than western samples. (Table 47). Regarding coping strategies, Saudi mothers used significantly more strategies than British mothers (p<.001) for all coping sub-scales (Pitten Cate, 2003). Only British mothers showed significantly more acceptance than Saudi mothers (p<.05).

Table 47: Mean differences between western and Saudi mothers of disabled children

| Questionnaire | t | Df | Sig (2-tailed) |
|---|---|---|---|
| PSI-SF | 10.89 | 400 | .00 |
| Brief COPE | 41.23 | 437 | .00 |
| Self-distraction | 15.36 | 444 | .00 |
| Active coping | 14.78 | 454 | .00 |
| Denial | 15.39 | 448 | .00 |
| Substance use | 3.86 | 451 | .00 |
| Use of emotional support | 10.92 | 449 | .00 |
| Use of instrumental support | 11.19 | 445 | .00 |
| Behavioural disengagement | 14.91 | 443 | .00 |
| Venting | 15.19 | 445 | .00 |
| Positive reframing | 15.27 | 463 | .00 |
| Planning | 18.03 | 461 | .00 |
| Humour | 8.35 | 493 | .00 |
| Acceptance | -2.20 | 443 | .02 |
| Religion | - | - | - |
| Self-blame | 9.29 | 443 | .00 |
| SPS | -32.38 | 350 | .00 |
| FSS | 8.94 | 406 | .00 |
| HADS | 4.73 | 504 | .00 |
| Anxiety | 4.40 | 505 | .00 |
| Depression | 4.12 | 504 | .00 |
| SDQ | 12.55 | 452 | .00 |

### 9.5.5. Answering question 4:

### Differences in stress, coping, social support, and mental health problems between Saudi mothers of TD children and mothers of children with ID:

In order to answer this question, we compared the results for mothers of children with ID with those mothers of TD children, using an independent sample t-test.

Table 49 shows significant differences between the two samples in terms of parenting stress. More stress was reported by mothers of ID children than by mothers of TD children. It also showed a significant difference in the use of all coping strategies between the two samples: the problem-focused coping strategy was used more by mothers of TD children (Mean=47.62) than by mothers of ID children. For emotion-focused coping, results revealed significant differences between the two groups. The emotion-focused coping strategy was used more by mothers of TD children than by mothers of disabled children. Regarding religious coping, there were significant differences between the two groups, with religious and spiritual coping used more by mothers of ID children than by those with TD children.

Regarding social support, there was a significant difference between the two samples in the satisfaction with support (social provision scale), more satisfaction with social support was reported by mothers of TD children than by mothers of ID children. In the level of helpfulness of social support (FSS), there was also a significant difference between the two samples, higher levels of helpfulness of social support using the family support scale were reported by mothers of TD children than by mothers of ID children. Regarding the number of sources of support, mothers of TD children had a larger network size than those of children with ID which was a significant difference between the two samples.

According to mental health status, Table 49 shows that there were significant differences between the two samples in levels of anxiety and of depression with a higher level of anxiety and depression shown by mothers of ID children than by those of TD children. In general, more mental health problems (anxiety and depression) were reported by mothers of disabled children than by mothers of TD children (Table 49).

Table 48: Descriptive statistics of mothers of typically developing and intellectually disabled children

| *Variable* | *Sample* | *N* | *M* | *SD* |
|---|---|---|---|---|
| PSI-SF | TD | 461 | 88.22 | 29.41 |
| | ID | 401 | 109.40 | 22.17 |
| Brief COPE | TD | 461 | 83.94 | 16.68 |
| | ID | 438 | 78.27 | 14.79 |
| Problem-focused coping | TD | 470 | 47.62 | 10.64 |
| | ID | 440 | 44.21 | 9.47 |
| Emotion focused coping | TD | 476 | 21.68 | 6.88 |
| | ID | 441 | 19.16 | 6.21 |
| Religious/spiritual coping | TD | 482 | 14.53 | 2.23 |
| | ID | 445 | 14.92 | 2.31 |
| SPS | TD | 463 | 77.49 | 13.84 |
| | ID | 451 | 72.73 | 10.07 |
| Level of helpfulness (FSS) | TD | 468 | 34.52 | 16.01 |
| | ID | 407 | 31.09 | 17.58 |
| Number of sources of support (FSS2) | TD | 468 | 12.54 | 3.97 |
| | ID | 405 | 11.42 | 4.87 |
| Anxiety | TD | 486 | 8.16 | 4.41 |
| | ID | 506 | 8.89 | 4.98 |
| Depression | TD | 486 | 3.61 | 2.96 |
| | ID | 505 | 5.95 | 3.94 |
| HADS | TD | 486 | 11.77 | 6.72 |
| | ID | 505 | 14.85 | 8.08 |

Table 49: Mean differences between the 2-groups (TD &ID) using independent t-test

| *Variable* | t | df | Sig. | M. differences |
|---|---|---|---|---|
| PSI-SF | -11.79 | 860 | .00 | -21.18 |
| COPE | 5.38 | 897 | .00 | .566 |
| Problem-focused coping | 5.09 | 908 | .00 | .3.41 |
| Emotion focused coping | 5.80 | 915 | .00 | 2.52 |
| Religious/spiritual coping | -2.65 | 925 | .00 | -.39 |
| SPS | 5.43 | 812 | .00 | 4.75 |
| Level of helpfulness (FSS) | 3.02 | 873 | .00 | 3.43 |
| Number of sources of support (FSS2) | 3.73 | 871 | .00 | 1.12 |
| Anxiety | -2.45 | 990 | .01 | -.73 |
| Depression | -10.53 | 989 | .00 | -2.34 |
| HADS | -6.51 | 989 | .00 | -3.08 |

### 9.5.2. Answering question 5:

Factor analysis is one of the most well-established methods of exploring and simplifying data (Stevenson, 1989). The most common use of factor analysis is to reduce data and to understand the structure and interrelationship between the underlying dimensions (Stevenson, 1993).

Answering the fifth question, factor analysis has been used in order to reduce some of the sub-scales of some questionnaires or combine some of them together. Moreover, we wanted to ensure that the translated questionnaires had the same factors as the originals and, if not, how they differed. To evaluate the factor structure of the PSI-SF, Brief COPE, SPS, FSS, HADS and SDQ, an exploratory factor analysis was conducted in response to the instruments. The sample of 1,017 that was described earlier provided data for the analyses of the PSI-SF, Brief COPE, SPS, FSS, and HADS. Factor analyses were tested for each group independently and additionally for the whole sample together. For testing the SDQ factor analysis, only the ID group was included. A covariance matrix was computed based on the responses of participants. A principle component factor analysis with varimax rotation was used. Using the Scree test, which is generally used as the most suitable technique for deciding the number of factors to extract (Kline, 1994),

All the PSI-SF items loading on their respective factors were significant and sizable (ranging from .42 to .74) for the TD group and .43 to .74 for the ID group. Table 50 revealed that four factors were extracted. There was an unambiguous change in slope on the scree plot at four factors of PSI-SF when used with the TD group (see Appendix 11). This measure factored as mentioned in Abidin (1995), parental distress (PD), parent-child dysfunctional interaction (P-CDI) and difficult child (DC). However, only items 2, 6 and 8 failed to coincide with items from their factor as mentioned in the literature. The total Eigen values of all the factors were greater than 1. They were 15.36 (% of variance= 42.66) for the first factor, 2.06 (% of variance 5.72) for the second factor, 1.67 (% of variance 4.64) for the third factor, and 1.20 (% of variance 3.34) for the fourth factor. (see Appendix 11 for PSI-SF scree plot).

Regarding the ID group, results revealed 4 extracted factors of PSI-SF. There was an unambiguous change in slope on the scree plot at four factors (see appendix 11). Factors repeated those mentioned in the literature that PSI-SF consists of three subscales (parental distress, parent-child dysfunctional interaction, and difficult child) (Abidin, 1995). However, only items 2, 13, 18 and 22 did not coincide with their subscales mentioned in the literature. Eigen values were greater than 1 for all factors, being 9.50 (% of variance 26.40) for the first factor, 2.51 (% of variance 6.99) for the second factor, 1.86 (% of variance 5.18%) for the third factor, 1.45 (% of variance 4.04) for the fourth factor.

Table 50: Varimax Rotated factor solution for the PSI- SF

| | TD | | | | | ID | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | | 1 | 2 | 3 | 4 |
| PSI29 | .74 | | | | PSI28 | .74 | | | |
| PSI34 | .71 | | | | PSI29 | .67 | | | |
| PSI30 | .71 | | | | PSI27 | .67 | | | |
| PSI28 | .70 | | | | PSI24 | .62 | | | |
| PSI36 | .66 | | | | PSI25 | .61 | | | |
| PSI27 | .66 | | | | PSI34 | .58 | | | |
| PSI31 | .63 | | | | PSI30 | .57 | | | |
| PSI25 | .62 | | | | PSI26 | .57 | | | |
| PSI26 | .58 | | | | PSI35 | .50 | | | |
| PSI24 | .57 | | | | PSI33 | .50 | | | |
| PSI35 | .51 | .44 | | | PSI32 | .49 | | | |
| PSI33 | .47 | | | | PSI31 | .46 | | | |
| PSI15 | | .74 | | | PSI36 | .44 | | | |
| PSI14 | | .72 | | | PSI22 | .30 | | | |
| PSI18 | | .63 | | | PSI11 | | .70 | | |
| PSI19 | | .63 | | | PSI12 | | .66 | | |
| PSI17 | | .62 | | | PSI5 | | .65 | | |
| PSI23 | .40 | .60 | | | PSI9 | | .64 | | |
| PSI20 | | .58 | | | PSI4 | | .63 | | |
| PSI16 | | .58 | | | PSI8 | | .61 | | |
| PSI21 | | .51 | | | PSI10 | | .58 | | |
| PSI13 | .44 | .47 | | | PSI7 | | .51 | | .40 |
| PSI3 | | | .70 | | PSI6 | | .47 | | |
| PSI11 | | | .65 | | PSI1 | | .37 | | |
| PSI7 | | | .62 | | PSI19 | | | .71 | |
| PSI12 | | | .61 | | PSI15 | | | .58 | |
| PSI2 | .51 | | .60 | | PSI20 | | | .56 | |
| PSI10 | | | .59 | | PSI17 | | | .54 | |
| PSI4 | | | .58 | | PSI23 | | | .53 | |
| PSI9 | | | .56 | | PSI21 | | | .48 | .38 |
| PSI1 | .40 | | .52 | | PSI14 | | .42 | .45 | |
| PSI5 | | | .50 | | PSI16 | | | .43 | |
| PSI22 | | | | .60 | PSI2 | | | | .68 |
| PSI6 | | | | .54 | PSI3 | | .42 | | .52 |
| PSI8 | | .44 | | .53 | PSI18 | | | .47 | .49 |
| PSI32 | .42 | | | .49 | PSI13 | | | | .29 |

Factor analyses for the whole sample combined together (N= 1017) were examined and all the PSI-SF items loading on their respective factors were satisfactorily significant and sizeable (ranging from .40 to .75). Using the the scree test which revealed that three factors of PSI-SF were extracted. There were clear changes in slope for three factors (see Appendix 12). The first factor consists of 16 items and three items were second-order factor loading. Items 25 to 36, the DC sub-scale items, were included in this factor.

The second factor consisted of 10 items with one is a second-order factor loadings. Items 13 to 23 are the P-CDI sub-scale. Only item 24, which is one of the P-CDI items in the original PSI-SF, did not factor with the second factor and it was included in the first factor's items.

Finally, the third factor consisted of 10 items and three were second-order factor loading. Items 1 to 12, except item 2, were included in this factor. These are the PD sub-scale items in the original PSI-SF. Only item 2 was omitted from this factor although it was in the original PSI-SF (Abidin, 1995). The total Eigen values of all factors are greater than 1: 13.65 (%of variance 37.94) for the first factor, 2.14 (% of variance= 5.94) for the second variable and 1.82 (% of variance 5.06) for the third factor.

Table 51: Extracted PSI-SF Rotated Component Matrix (N= 1017)

| | 1 | 2 | 3 |
|---|---|---|---|
| PSI29 (difficult child) | .78 | | |
| PSI28 (difficult child) | .74 | | |
| PSI34 (difficult child) | .74 | | |
| PSI27 (difficult child) | .69 | | |
| PSI30 (difficult child) | .67 | | |
| PSI2 (parental distress) | .65 | | |
| PSI24 (parent-child dysfunctional interaction) | .61 | | |
| PSI25 (difficult child) | .59 | | |
| PSI36 (difficult child) | .57 | | |
| PSI31 (difficult child) | .56 | | |
| PSI26 (difficult child) | .53 | | |
| PSI3 (parental distress) | .48 | | (.45) |
| PSI13 (parent-child dysfunctional interaction) | .47 | (.44) | |
| PSI1 (parental distress) | .44 | | (.43) |
| PSI33 (difficult child) | .42 | | |
| PSI32 (difficult child) | .38 | | |
| PSI19 (parent-child dysfunctional interaction) | | .71 | |
| PSI18 (parent-child dysfunctional interaction) | | .68 | |
| PSI15 (parent-child dysfunctional interaction) | | .67 | |
| PSI20 (parent-child dysfunctional interaction) | | .64 | |
| PSI14 (parent-child dysfunctional interaction) | | .59 | (.40) |
| PSI17 (parent-child dysfunctional interaction) | | .58 | |
| PSI21 (parent-child dysfunctional interaction) | (.41) | .57 | |
| PSI23 (parent-child dysfunctional interaction) | | .56 | |
| PSI16 (parent-child dysfunctional interaction) | | .50 | |
| PSI35 (difficult child) | (.42) | .45 | |
| PSI11 (parental distress) | | | .70 |
| PSI9 (parental distress) | | | .66 |
| PSI12 (parental distress) | | | .63 |
| PSI8 (parental distress) | | | .60 |
| PSI4 (parental distress) | | | .59 |
| PSI5 (parental distress) | | | .58 |
| PSI10 (parental distress) | | | .58 |
| PSI7 (parental distress) | (.45) | | .55 |
| PSI6 (parental distress) | | | .46 |
| PSI22 (parent-child dysfunctional interaction) | | | .38 |

Unlike the other scales, a second order factor analysis was used with the Brief COPE (Table 52). That means we entered sub-scales instead of items into the analysis. That is because the Brief COPE consisted of 14 subscales and we added one subscale (belief), making 15 subscales. Each subscale included only two items, which made it difficult to include all these items in factor analyses. Moreover, Carver (1997) already tested the factor analysis of this scale (the results of Carver's study revealed six factors). So, we found it more useful to include subscales in the equation instead of including all items as we did with other scales.

A Varimax rotational analysis for the Brief COPE Scale for each sample was carried out independently (Table 52). Three orthogonal factors emerged which accounted significantly from .63 to .85 for the TD group. The first factor consisted of positive reframing, acceptance, active coping, venting, planning, emotional support, self-blame, and instrumental support. The second factor consisted of five items: behavioural disengagement, denial, substance use, humour, and self-distraction. Finally, the third factor consisted of only two items: religion and belief. The total Eigen values for all factors were greater than one: 6.25 (% of variance= 41.69) for the first factor, 1.75 (% of variance= 11.68) for the second factor, and 1.04 (% of variance= 6.94) for the third factor (see Appendix 11 for the Brief COPE scree plot)

For the ID group three factors were also found, the result of which were shown in Table 52. Factor analyses for this group replicated the results in the TD group, except for the "instrumental support" items, which did not factor with any of the three factors. The total Eigen value for all factors was greater than one: 4.92 (% of variance= 32.82%) for the first factor, 1.91 (% of variance= 12.73) for the second factor and 1.138 (% of variance= 7.58) for the third factor.

Table 52: Varimax Rotated factor solution for the Brief COPE subscales

| | TD | | | ID | | | |
|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | | 1 | 2 | 3 |
| Positive reframing | .79 | | | Planning | .73 | | |
| Acceptance | .78 | | | Positive reframing | .68 | | |
| Active coping | .73 | | | Active coping | .66 | | |
| Venting | .71 | | | Acceptance | .65 | | |
| Planning | .70 | | | Venting | .55 | .48 | |
| Emotional support | .69 | | | Self-blame | .50 | .48 | |
| Self-blame | .64 | | | Emotional support | .48 | | |
| Instrumental support | .63 | | | Behavioural disengagement | | .77 | |
| Behavioural-disengagement | | .80 | | Substance use | | .73 | |
| Denial | | .74 | | Denial | | .72 | |
| Substance use | | .63 | | Humour | | .55 | |
| Humour | (.42) | .55 | | Self distraction | .42 | .49 | |
| Self distraction | (.43) | .55 | | Belief | | | .87 |
| Belief | | | .85 | Religion | | | .86 |
| Religion | | | .79 | Instrumental support | | | .37 |

Factor analyses for the whole sample (N= 1017) have been tested (Table 53). A Varimax rotational analysis for the Brief COPE Scale was also carried out and three orthogonal factors emerged. The first factor consisted of positive reframing, acceptance, active coping, venting, planning, emotional support, self-blame, and instrumental support. The second factor consisted of five items: behavioural disengagement, denial, substance use, humour, and self-distraction. Finally, the third factor consisted of only two items: religion and belief. The total Eigen values for all factors were greater than one: 5.64 (% of variance= 37.64) for the first factor, 1.86 (% of variance= 12.40) for the second factor, and 1.101 (% of variance= 7.33) for the third factor. (see Appendix 12 for the Brief COPE scree plot)

Table 53: Brief COPE Rotated Component Matrix (N=1017)

| | 1 | 2 | 3 |
|---|---|---|---|
| Positive reframing | .74 | | |
| Acceptance | .73 | | |
| Planning | .71 | | |
| Active coping | .70 | | |
| Venting | .66 | | |
| Using emotional support | .62 | | |
| Self blame | .58 | (.42) | |
| Using instrumental support | .50 | | |
| Behavioural disengagement | | .80 | |
| Denial | | .74 | |
| Substance use | | .69 | |
| Humour | (.43) | .53 | |
| Self-distraction | (.45) | .51 | |
| Belief | | | .85 |
| Religion | | | .84 |

For the SPS (Table 49) with Varimax rotation analyses, three factors emerged (from .74 to .46) for the TD group and (from .76 to .40) for the ID group. For the TD group, three factors resulted with the Arabic sample instead of the six that were in the original scale (Russell and Cutronna, 1984). The first factor consisted of 11 items, the second factor of 8 items, and the third of 5. The method of factoring these items was different from that in the original study. The first factor contained all the positive items in all subscales except for item 8 in the "social integration" subscale. The second factor consisted of the two negative items of "reassurance of worth" and "attachment", and one negative item from "guidance", "social integration", "nurturance", and "reliable alliance". The third factor consisted of two negative and one positive item from "social integration" subscale, one negative item from "guidance", "nurturance", and "reliable alliance". The total Eigen values for all factors were greater than 1: 10.27 (% of variance= 42.82) for the first factor, 1.36 (% of variance= 5.69) for the second factor, and 1.09 (% of variance= 4.56) for the third factor. (see Appendix 11 for the SPS scree plot)

Regarding the TD group, the scree plot test was used to decide the number of factors to extract as a result of which three factors were extracted, because there was a clear change in slope on the scree plot at three factors (see Appendix 11). Table 54 reveals very different factors from those in the original study, but similar factors to the TD group. Using the scree test, four factors were extracted. There was an unambiguous change in slope on the scree plot at four factors. The results of factor analysis are shown in Table 54. Almost all items were factored similarly to the TD group except for items 8, 18 and 22. The total Eigen value for all factors was greater than 1: 5.66 (% of variance= 23.59) for the first factor, 2.42 (% of variance= 10.11) for the second factor, and 1.63 (% of variance= 6.79) for the third factor, and 1.27 (% of variance= 5.32) for the fourth factor.

Table 54: Varimax Rotated factor solution for the SPS

| TD | | | | ID | | | | |
|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | | 1 | 2 | 3 | 4 |
| 11 (attachment +) | .71 | | | 12 (guidance +) | .76 | | | |
| 4 (nurturance +) | .69 | | | 16 (guidance +) | .68 | | | |
| 12 (guidance +) | .67 | | | 11 (attachment +) | .63 | | | |
| 16 (guidance +) | .64 | | | 13 (reassurance of worth +) | .62 | | | |
| 1 (reliable alliance +) | .62 | | | 20 (reassurance of worth +) | .62 | | | |
| 5 (social integration +) | .62 | | | 1 (reliable alliance +) | .54 | | | |
| 13 (reassurance of worth +) | .57 | | | 5 (social integration +) | .49 | | | |
| 20 (reassurance of worth +) | .54 | | | 17 (attachment +) | .48 | | | |
| 17 (attachment +) | .53 | | | 23 (reliable alliance +) | .47 | | | |
| 23 (reliable alliance +) | .51 | | (.49) | 19 (guidance -) | | .68 | | |
| 7 (nurturance +) | .47 | | (.45) | 18 (reliable alliance -) | | .68 | | |
| 2 (attachment -) | | .76 | | 14 (social integration -) | | .66 | | |
| 21 (attachment -) | | .62 | | 15 (nurturance -) | | .59 | | .49 |
| 3 (guidance -) | | .62 | | 24 (nurturance -) | | .48 | | .43 |
| 9 (reassurance of worth -) | | .59 | | 10 (reliable alliance -) | | .40 | | |
| 14 (social integration -) | | .57 | (.45) | 22 (social integration -) | | (.39) | | |
| 10 (reliable alliance -) | | .50 | | 6 (reassurance of worth -) | | | .71 | |
| 15 (nurturance -) | | .47 | .43 | 2 (attachment -) | | | .66 | |
| 6 (reassurance of worth -) | | .46 | .39 | 21 (attachment -) | | | .58 | |
| 19 (guidance -) | | | .74 | 9 (reassurance of worth -) | | (.42) | .55 | |
| 18 (reliable alliance -) | | | .72 | 3 (guidance -) | | | .44 | |
| 22 (social integration -) | | | .61 | 7 (nurturance +) | | | | .75 |
| 8 (social integration +) | | | .51 | 4 (nurturance +) | | | | .60 |
| 24 (nurturance -) | | | .46 | 8 (social integration +) | (.46) | | | .49 |

Testing factor analyses with the whole sample (N= 1017) (Table 55) for SPS, Varimax rotational analyses showed factors from .76 to .47 Four factors where extracted that showed an unambiguous change in slope on the scree plot (see Appendix 12). Results in Table 55 show that the result of factoring these items was different from that resulted in the original study (Russel & Cuttrona, 1984). The first factor contained 10 positive items from all subscales, one of these items (item 9) was a second-order factor loading (.45). Two positive items emerged from the reassurance of worth, attachment, social integration, guidance, and reliable alliance.

The second factor consisted of 10 negative items from each subscales. It consisted of two negative items from each of the reassurance of worth, attachment, social integration, guidance, and reliable alliance. The third factor consisted of five items. There were four negative and a positive items in the "nurturance" subscale. Item 8 was a second-order factor loading with factor 1(.45). The total Eigen values for all factors were greater than 1: 8.45 (% of variance= 35.21) for the first factor, 1.73 (% of variance= 7.22) for the second factor, and 1.21 (% of variance= 5.04) for the third factor. (see Appendix 12 for the SPS scree plot)

Table 55: Rotated Component Matrix of the extracted SPS (N=1017)

| | 1 | 2 | 3 |
|---|---|---|---|
| SPS12- there is someone I could talk to about important decisions.. | .75 | | |
| SPS16- there is a trustworthy person I could turn to for advice.. | .72 | | |
| SPS11- I have close relationships that provide me with a sense of.. | .66 | | |
| SPS13 I have relationships where my competence and skills are recognized | .60 | | |
| SPS20- there are people who admire my talents and abilities | .59 | | |
| SPS1- there are people I can depend on to help me if I really need it. | .58 | | |
| SPS23- there are people who I can count on in an emergency | .57 | | |
| SPS17- I feel a strong emotional bond with at least one other person | .54 | | |
| SPS5 there are people who enjoy the same social activities as do. | .52 | | |
| SPS14 there is no one who shares my interests and concerns | | .65 | |
| SPS9- I do not think other people respect my skills and abilities | | .64 | |
| SPS3- there is no one I can turn to for guidance in times of stress | | .61 | |
| SPS6- other people do not view me as competent | | .60 | |
| SPS18- there is no one I can depend on for aid if I really need it | | .60 | |
| SPS19-there is no one I feel comfortable talking about problems with | | .57 | |
| SPS21- I lack a feeling of intimacy with another person | | .56 | |
| SPS2- I feel that I don't have close relationships with other people | | .56 | |
| SPS10 If something went wrong no-one comes to my assistance | | .53 | |
| SPS22 there is no one who likes to do the things I do | | .51 | |
| SPS7- I feel personally responsible for the well-being of another person | | | .72 |
| SPS4- there are people who depend on me for help | (.42) | | .59 |
| SPS15- there is no one who really relies on me for their well-being | | (.46) | .56 |
| SPS24- no one needs me to care for them | | (.47) | .49 |
| SPS8- I feel part of a group of people who share my attitudes and belief | (.45) | | .49 |

Table 56 shows four factors of the family support scale for both TD and ID groups. In the original study (Dunst, Trivitte & Hamby, 1993) there were five factors for this scale. For the TD group, husband's parents, husband's relatives, own relatives, own parents, husband, and husband's friends were combined in one factor. The second factor consisted of professional agencies, professional helpers, child's doctor, school, day-care centre, place of worship, and early intervention programme. The third factor consisted only of own children's and friends' support. The last factor consisted of co-workers, parents' group, and others parents' support. These factors were slightly different than the five factors found in the original study (Dunst et al., 1993). The total Eigen values for the four factors were greater than one: 6.83 (% of variance= 37.96) for the first factor, 2.33 (% of variance= 12.94) for the second factor, 1.22 (% of variance= .6.82) for the third factor, and 1.06 (% of variance= 5.91) for the fourth factor. (see Appendix 11 for the FSS scree plot)

For the ID group the results from four factors used are shown in Table 56. Social groups, co-workers, parents' group, husband's friends, other parents, place of worship/religious organisations, and own friends were combined in the first factor. Professional helpers, professional agencies, family or child's doctor, school/day-care centre, and early interventions programme were combined in the second factor. Own parents, own relatives, husband's parents, and husband's relatives were combined in the third factor, and husband and children comprised the fourth factor. The total Eigen values for the four factors was greater than one: 6.90 (% of variance= 38.34) for the first factor, 1.84 (% of variance= 10.23) for the second factor, 1.33 (% of variance= 7.41) for the third factor, and 1.00 (% of variance= 5.55) for the fourth factor (see Appendix 11 for the FSS scree plot).

Table 56: Varimax Rotated factor solution for the FSS

| | TD | | | | ID | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | | 1 | 2 | 3 | 4 |
| 2-Husband' parents | .82 | | | | 12-Social groups/ clubs | .78 | | | |
| 4- Husband's relative | .78 | | | | 10- Co-workers | .75 | | | |
| 3 Own relatives / kinship | .77 | | | | 11-Parent group | .72 | | | |
| 1- Own parents | .75 | | | | 7-Husband's Friends | .62 | | | |
| 5- Husband | .62 | | | | 9- Other parents | .60 | | | |
| 7- Husband's friends | .54 | | (.53) | | 13-Place of worship | .55 | .48 | | |
| 16- Professional agencies | | .76 | | | 6- Friends | .40 | | | |
| 15- professional helpers | | .67 | | | 15-professional helpers | | .83 | | |
| 14- Family or child's doctor | | .64 | | | 16-Professional agencies | | .79 | | |
| 17-School / day-care centre | | .62 | | | 14-Family/child's Doctor | | .75 | | |
| 12- Social groups/ clubs | | .62 | | | 17-School / day-care centre | | .61 | | |
| 13- Place of worship/ religious organization | | .59 | | | 18-Early intervention program | | .61 | | |
| 18- Early intervention program | | .57 | | | 1- Own parents | | | .80 | |
| 8- Own children | | | .81 | | 3-Own relatives / Kinship | | | .75 | |
| 6- Friends | (.43) | | .63 | | 2-Husband' parents | | | .67 | |
| 10- Co-workers | | | | .83 | 4-Husband's relative | | | .61 | |
| 11-Parent group | | | | .66 | 5- Husband | | | | .78 |
| 9- Other parents | | | | .48 | 8- Own Children | | | | .73 |

Table 57 shows four factors for the whole sample (N=1017). Six items were included in the first factor: husband, own relatives, own parents, husband's relatives, husband's parents and husband's friends were combined in the first factor. Whereas husband's friends was a second-order factor loading with factor 4 (.44). The second factor consisted of professional Agencies, professional helpers, child's doctor, school, day-care centre, early intervention programme and place of worship. The third factor consisted of four items: co-worker, parents' group, social group/club, and other parents. Finally, the fourth factor consisted of two items: own children and friends support. The total Eigen values for the four factors were greater than one: 6.76 (% of variance= 37.58) for the first factor, 2.04 (% of variance= 11.34) for the second factor, 1.24 (% of variance= 6.89) for the third factor, and 1.01 (% of variance= 5.64) for the fourth factor (see Appendix 12 for the FSS scree plot).

Table 57: Rotated Component Matrix of the FSS (N= 1017)

| | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| FSS2- Husband | .78 | | | |
| FSS3- my relative/kin | .76 | | | |
| FSS1- my parents | .76 | | | |
| FSS4- my husband's relatives/kin | .76 | | | |
| FSS5- Husband | .55 | | | |
| FSS7- My husband's friends | .49 | | | (.44) |
| FSS16- professional agencies | | .79 | | |
| FSS15- professional helpers | | .78 | | |
| FSS14- Family or child's doctor | | .66 | | |
| FSS17- school/ day-care centre | | .61 | | |
| FSS18- early intervention programme | | .59 | | |
| FSS13- place of worship/religious organisation | | .49 | .44 | |
| FSS10- co-worker | | | .79 | |
| FSS11- parent group | | | .73 | |
| FSS12- social group/club | | | .68 | |
| FSS9- other parents | | | .60 | |
| FSS8- my own children | | | | .80 |
| FSS6- my friends | (.40) | | (.38) | .41 |

The principle component Varimax rotation for the HADS for the TD and ID groups revealed that the HADS showed exactly the same factors when used with the Arabic population as had been reported in the original study (Zigmond and Snaith, 1983) and also for the Arabic translated HADS (El-Rufaie, 1987, El-Rufaie, 1993): the seven odd items for anxiety, and the seven even items for depression. The total Eigen values for the two factors were greater than one: for the typically developing group, 7.11 (% of variance= .83) for the first factor, and 1.55 (% of variance= 11.03) for the second factor (Table 58).

Moreover, the ID group, factored exactly as the TD group and as in previous studies. The seven odd items, the anxiety items, were combined in one factor and the seven even items, the depression items, were combined in the second factor. The total Eigen values were greater than one for the two factors: 7.54 (% of variance= 53.88) for the first factor, and 1.69 (% of variance= 12.07) for the second factor (see Appendix 11 for the HADS scree plot).

Table 58: Varimax rotated factor solution for the HADS

| TD group |  |  | ID group |  |  |
|---|---|---|---|---|---|
|  | 1 | 2 |  | 1 | 2 |
| HADS11 | .77 |  | HAD11 | .89 |  |
| HADS3 | .75 |  | HAD13 | .89 |  |
| HADS7 | .75 |  | HAD1 | .87 |  |
| HADS13 | .74 |  | HAD3 | .87 |  |
| HADS9 | .74 |  | HAD7 | .85 |  |
| HADS5 | .74 |  | HAD5 | .84 | .40 |
| HADS1 | .73 |  | HAD9 | .76 |  |
| HADS12 |  | .78 | HAD12 |  | .83 |
| HADS6 |  | .77 | HAD4 |  | .82 |
| HADS8 |  | .75 | HAD14 |  | .82 |
| HADS4 |  | .74 | HAD6 |  | .81 |
| HADS10 |  | .73 | HAD2 |  | .81 |
| HADS2 |  | .68 | HAD10 |  | .81 |
| HADS14 |  | .57 | HAD8 |  | .79 |

For both groups combined together (N=1017), the principle component varimax rotation for the HADS revealed that the HADS showed exactly the same factors when used with the Arabic population, results as had been reported in the original study (Zigmond & Snaith, 1983) and also for the Arabic translated HADS (El-Rufaie, 1987, El-Rufaie, 1993). The seven odd items for anxiety were combined in one factor, and the seven even items for depression were combined in another factor (Table 59). The total Eigen values for the two factors were greater than one: 7.41 (% of variance= .52.95) for the first factor, and 1.70 (% of variance= 12.21) for the second factor. (see Appendix 12 for the HADS scree plot).

Table 59: Rotated Component Matrix for HADS (N=1017)

|  | 1 | 2 |
|---|---|---|
| HADS11 (anxiety) | .80 |  |
| HADS7 (anxiety) | .79 |  |
| HADS3 (anxiety) | .78 |  |
| HADS13 (anxiety) | .78 |  |
| HADS5 (anxiety) | .77 |  |
| HADS1 (anxiety) | .77 |  |
| HADS9 (anxiety) | .73 |  |
| HADS12 (depression) |  | .78 |
| HADS4 (depression) |  | .75 |
| HADS6 (depression) |  | .75 |
| HADS10 (depression) |  | .74 |
| HADS8 (depression) |  | .73 |
| HADS14 (depression) |  | .72 |
| HADS2 (depression) |  | .71 |

Finally, The principle component Varimax rotational for the SDQ (Table 60) revealed that the SDQ results were five factors. The first factor consisted of five hyperactivity items. The second factor consisted of the five peer problems items and two conduct problems items. The third factor contained five emotional symptoms items and factor four has five prosocial items. Finally, factor five consisted of three conduct problems items. The total Eigen values for the five factors were greater than one: 11.43 (% of variance= 45.72) for the first factor, and 3.55 (% of variance= 14.20) for the second factor, 1.69 (% of variance= 6.78) for the third factor, 1.20 (% of variance= 4.83%) for the fourth factor and 1.12 (% of variance= 4.48) for the fifth factor (see Appendix 11 for the SDQ scree plot).

It is worth mentioning that the Arabic SDQ has the same number of factors and its factors are very similar to the original scale with only two items factoring differently in the Arabic scale, which are items 5 and 7.

Table 60: Rotated Component Matrix for the SDQ (N=513)

| | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| SDQ10 (Hyperactivity) | .85 | | | | |
| SDQ21 (Hyperactivity) | .84 | | | | |
| SDQ2 (Hyperactivity) | .81 | | | | |
| SDQ25 (Hyperactivity) | .81 | | | | |
| SDQ15 (Hyperactivity) | .77 | | | | |
| SDQ11 (Peer problem) | | .80 | | | |
| SDQ19 (Peer problem) | | .80 | | | |
| SDQ14 (Peer problem) | | .79 | | | |
| SDQ6 (Peer problem) | | .76 | | | |
| SDQ23 (Peer problem) | | .72 | | | |
| SDQ7 (Conduct problems) | | .46 | | | (.38) |
| SDQ5 (Conduct problems) | | .44 | | | (.38) |
| SDQ13 (Emotional symptoms) | | | .75 | | |
| SDQ8 (Emotional symptoms) | | (.42) | .74 | | |
| SDQ3 (Emotional symptoms) | | (.42) | .73 | | |
| SDQ24 (Emotional symptoms) | | | .69 | | |
| SDQ16 (Emotional symptoms) | | (.45) | .68 | | |
| SDQ9 (Prosocial) | | | | .86 | |
| SDQ4 (Prosocial) | | | | .84 | |
| SDQ17 (Prosocial) | | | | .83 | |
| SDQ1 (Prosocial) | | | | .76 | |
| SDQ20 (Prosocial) | | | | .66 | |
| SDQ12 (Conduct problems) | | | | | .77 |
| SDQ22 (Conduct problems) | | | | | .77 |
| SDQ18 (Conduct problems) | | | | | .76 |

**Retesting reliability for the new factors:**

In order to ensure that the internal consistency of the scales were still applicable, Cronbach's alpha were tested for the new factors of the PSI-SF, Brief COPE, SPS, and FSS. Because the HADS and SDQ showed exactly the same factors as in the original studies, there was no need to retest the internal consistency for them again.

Table 61 examines the internal consistency of the PSI-SF. Although the factor analysis results of this questionnaire showed almost the same factors as the original study, we thought it might be useful to retest the reliability of this scale, because of the three items that showed different factors from those in the literature. Table 61 reveals a high alpha level for the three sub-scales.

Table 61: Internal consistency of the new PSI-SF sub-scales

| | N. Cases | N. Items | Alpha |
|---|---|---|---|
| 1. Parental distress (PD) | 899 | 16 | .91 |
| 2. Parent-child dysfunctional interaction (P-CDI) | 921 | 10 | .88 |
| 3. Difficult child (DC) | 905 | 10 | .84 |

For the Brief COPE, Table 62 examined the internal consistency for the three new coping strategies. Results showed a moderate level of alpha for all of the three subscales.

Table 62: Internal consistency of the new Brief COPE sub-scales

| | N. Cases | N. Items | Alpha |
|---|---|---|---|
| 1. Use of problem-focused coping | 912 | 7 | .85 |
| 2. Use of emotion-focused coping | 719 | 6 | .78 |
| 3. Use of religious coping | 927 | 2 | .76 |

In order to retest the reliability of the SPS, new factors were entered into the internal consistency equation. Although the results of factor analysis in Table 63 shows three factors of the SPS, all items in the third factors were second order factor loading with either the first or the second factor except for (item 7- "I feel personally responsible for the well-being of another person") which did not relate to either factor. Hence, all the negative items were combined in the first factor and all the positive items in the second.

Only item 7 was excluded from the analysis. Table 63 reveals a high level of alpha for both sub-scales.

Table 63: Internal consistency of the new SPS sub-scales

| | N. Cases | N. Items | Alpha |
|---|---|---|---|
| 1. Positive items | 866 | 11 | .87 |
| 2. Negative items | 858 | 12 | .86 |

Table 64 shows the internal consistency for the FSS new sub-scales. All four sub-scales showed a moderate and acceptable level of alpha.

Table 64: Internal consistency of the new FSS sub-scales

| | N. Cases | N. Items | Alpha |
|---|---|---|---|
| 1. Family support | 894 | 5 | .81 |
| 2. Instrumental formal support | 892 | 6 | .83 |
| 3. Informal support | 891 | 4 | .80 |
| 4. Offspring and friends' support | 900 | 3 | .62 |

## 9.6. CONCLUSION:

The basic issue addressed in the present study was an exploration of the reliability and validity of all questionnaires when used with a large sample. Moreover, one important issue was to find whether the structure of the scales was different when used in different cultures and how far each of the Arabic-translated scale factors differ from the original English scales

Firstly, only ID mothers obtained a total score higher then 90, which means they experiencing clinically significant levels of stress (Abidin,1995). According to Abidin (1995), the need for intervention in the form of short-term parental consultation or parent-education class focused on management strategies should be sufficient to help the situation.

Secondly, results showed a significant correlation between all the questionnaires. In addition, the internal correlation was significant for all sub-scales. However, some of the Brief COPE subscales did not correlate significantly, due to the small number of items in each sub-scale (two) and the large number of subscales (15 subscales). Internal consistency was high and applicable for all scales and subscales. These results confirmed the findings in the previous chapter (Chapter 8) concerning the use of these questionnaires with an Arabic sample, that they proved to be reliable and valid.

The internal consistency for all six questionnaires is considered satisfactory: although some of the SPS and the Brief COPE subscales showed a low level of alpha, we believe they fall within the acceptable range.

Thirdly, from the differences between the Saudis and the western in all of the study variables, it was obvious that Saudi mothers were more stressed, have more mental health problems, less social support even though they used more coping strategies than western mothers. Similar cultural differences were shown to exist between mothers of ID children.

Differences between Saudi mothers of TD and of ID children in term of stress, coping, social support, and mental health problems (anxiety and depression) were significant across all scales. Mothers of ID children showed significantly higher levels of maternal stress and mental health problems (anxiety and depression) than mothers of TD children. They reported significantly lower levels of social support (support satisfaction, number of sources of support and helpfulness of social support) than mothers of TD children. Regarding coping strategies and maternal well-being, mothers of ID children were more stressed, anxious, and depressed and focused on religious coping strategy more than mothers of TD children who focused significantly more on emotion-focused and religion-focused coping than mothers of ID children.

Finally, when we compared the factor structure between TD and ID groups with all scales (PSI-SF, Brief COPE, SPS, FSS, and HADS) only a few differences were reported in factor analysis between these two samples. However, when we compared these results with those in the literature, sometimes the results showed differences in the division of the sub-scales in each questionnaire (e.g. SPS) and sometimes there were no differences between these results and those in the literature (e.g. HADS and SDQ).

For the PSI-SF, the original study (Abidin, 1995), three factors were reported for the short form of the PSI: parental distress (PD), parent child dysfunctional interaction (P-CDI), and difficult child (DC). In this study, results revealed three factors of this scale. The factors newly introduced to the Arabic PSI-SF are: DC 12 items, P-CDI 10 items, PD 11 items. Only items 2, 22 and 24 have not factored as in the original study. Factor 2. ("I find myself giving up more of my life to meet my children's needs than I ever expected") is one of the PD items in Abidin's, whereas it joins DC items when used with Arabic mothers. Items 22 ("I feel I am: 1. not very good at being parent – 5. a very good parent") and 24 ("Sometimes my child does things that bother me just to be mean") both were P-CDI items in the original PSI-SF however, when used with Arabic mothers item 22 factored with PD and item 24 with DC items. That added one item to DC and one to PD.

According to the Arabic Brief COPE, three main subscales could be considered: first, "*problem-focused coping*", which consists of fourteen items, positive reframing, acceptance, active coping, venting, planning, emotional support, and instrumental support items. The second subscale was an "*emotion-focused coping*", which contained twelve items, behavioural disengagement, denial, substance use, humour, self-distraction and self-blame. The third sub-scale was *"religious coping"* which has four items, religion and belief items. It is worth mentioning that interpretation of factor analysis is not always straightforward and an element of judgement is needed. So, although self-blame loads higher on problem-focused it fits conceptually much better with emotion-focused as it does across a range of literature (e.g. Mitchell & Hastings, 2001; Pit-ten Cate, 2003). In addition, on the basis of one finding in this study and according to the results of the factor analysis, self-blame was considered as a second-order factor loading with the emotion-focused coping (.42) and this second result replicated what was reported in the literature which means that this subscale showed an acceptable level in both factors, so we believe it is logical for this subscale to be included with the other emotion-focused coping subscales.

This result is different from that of the original study, the Carver study (1997), in which more factors were reported (five). It is worth mentioning that factor analysis results in the Brief COPE study (Carver, 1997) were also not exactly the same as those found in the COPE study (Carver et al., 1989).

The Arabic SPS factored in a complete different way from the original scale. The Arabic questionnaire has three sub-scales, the first consisting of 10 positive items and we might call this the positive provision support sub-scale. The second factor consisted of ten negative items and we might call this the negative provision support sub-scale. The third factor was the nurturance sub-scale which has two negative and two positive items.

The FSS factors were slightly different from the five factors, which were included in the original study. The Arabic FSS consisted of four sub-scales. The first is *"family support*" which consists of five items: husband's parents, husband's relatives, own relatives, own parents, husband. The second factor was the *"instrumental formal support"*, which consists of six items: professional agencies, professional helpers, child's doctor, school, day-care centre, place of worship, and early intervention programme. The third factor was *"informal social support"* consisting of four items: co-worker, parent group, social group/club, and other parents. Finally, the fourth factor is the "offspring and friend support" with three items: my friends, my husband's friends and my children.

The factor analytic approach of the HADS identified that there were two dimensions of this scale. The results were exactly the same as those reported in the literature (Zigmond, & Snaith, 1983). The seven odd items represented the first factor and the seven even items represented the second factor. Finally, the Arabic SDQ results were similar to Goodman's.

It has five factors, each consisting of five items: emotional symptom, conduct problems, hyperactivity, peer problems and prosocial scale.

When we retested the reliability of the new factors of the questionnaire, internal consistency was examined with PSI-SF, SPS, Brief COPE, and FSS. The alpha level for all of the sub-scale was high or acceptable.

# CHAPTER 10

# TESTING THE MODEL (STUDY FOUR)

## 10.1. Introduction:

In the preceding two chapters validity and reliability (Chapter 8), factor analysis of the Arabic questionnaires and differences between groups which in all of the study variables were tested (Chapter 9). The primary aim of this empirical chapter is to explore the relationship between variables in order to examine the study model (see Figure 11, Chapter 4). Many predictions presented in the model were completely or partially consistent with what was mentioned in the literature. In addition, some of the predictions in the model had not been previously mentioned in the literature (e.g. family structure moderates the effect of child disability on maternal well-being). In this chapter mediating and moderating paths are tested for all the study variables.

## 10.2. Purpose of the study:

This analysis addressed questions related to stress and mental health problems (anxiety and/or depression) among mothers of children with ID in Saudi Arabia. The general purpose of this analysis was to introduce a hypothesised model, which investigated the relation between a mother's psychological well-being (stress, anxiety and depression) and other factors (coping strategies, family structure, and social support). In addition, the study explored the effect of family, child, and mother demographic characteristics on maternal well-being and then controlled for the significant ones in order to test the prediction of maternal well-being, using information about the child's Behavioural Disorders (BD) and IQ.

Three specific research questions are addressed:

**Question 1 (the link between child adjustment and maternal well-being):** Does child IQ or BD predict maternal well-being (stress, anxiety and depression) after controlling for other factors?

**Question 2 (mediation):** Are the links between child disability and maternal well-being (stress, anxiety, and depression) mediated by coping strategies and social support?

**Question 3 (moderation):** Are the links between child disabilty and maternal well-being moderated by coping strategies, social support and family structure?

## 10.3. Methods:

### 10.3.1. Participants:

In this study, only mothers of ID children were included in the data analysis. Data from 513 mothers of ID children were used to test the study model. For information about the characteristics of the sample and descriptive data on questionnaire scores, see Chapter 9.

### 10.3.2. Measures:

The measures used in this chapter have been described in detail in Chapter 6 and used with participants in Chapters 8 and 9:

1. The Parenting Stress Index (PSI-SF) (Abidin, 1995)
2. The Brief COPE Scale (Carver, 1997)
3. The Social Provision Scale (SPS) (Russel & Cutrona, 1984)
4. The Family Support Scale (FSS) (Dunst, et al, 1993)
5. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
6. The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997)
7. The demographic data scale.
8. As recorded in the students' school files, IQ was tested by the school doctors or social workers using the Stanford-Binet intelligence scale. Chapter 6 explained in detail how we acquired these data.

## 10.4. Results:

**Question 1 (the link between child adjustment and maternal well-being): Does child IQ or BD predict maternal well-being (stress, anxiety and depression) after controlling for other factors?**

In order to answer this question, the correlation matrix (Table 65) of demographic characteristics and maternal well-being (stress, anxiety and depression) were tested, and only those with significant associations were included in the regression analyses.

The results in Table 65 show that only child age has a significant correlation with all maternal outcomes (stress, anxiety and depression). Child gender and disability in another family showed significant correlation with maternal stress and depression. Whereas, other disability (when the child has another disability combined with an intellectual disability such as visual, hearing or physical disabilities) and family income were significant with maternal stress and anxiety. Furthermore, polygamy showed a significant correlation with maternal stress. These six characteristics were controlled for in Table 66 in order to find which type of child disability might be most stressful to mothers, BD or IQ and they will be treated as control variables in all further regression analyses. It is worth mentioning that type of disability (Down's syndrome, autism, cerebral palsy, hydrocephalus, disability with unknown aetiology) has been excluded from the correlation analyses because of the high percentage of those children with unknown aetiology (47%). Categorical variables, with more than two categories, have been transferred into binary dummy variables.

Table 65: Correlation between family characteristics and child disability

| Demographic variables* | Stress | Anxiety | Depression |
|---|---|---|---|
| **Child age** | -.21** | -.13** | -.09* |
| **Child gender** | -.17** | -.07 | -.16** |
| Birth order | -.00 | .00 | -.02 |
| Child education level | -.08 | -.01 | .00 |
| **Other disabilities** | -.14** | -.09* | -.08 |
| Type of school | .06 | .08 | .00 |
| **Disability in family** | -.19** | -.09* | .13** |
| Age of mother | .03 | -.02 | .02 |
| Age of father | .03 | -.03 | .04 |
| Parents kinship | .02 | -.01 | -.01 |
| Maternal marital status | -.01 | -.04 | -.03 |
| Number of children | .08 | .08 | .06 |
| **Polygamy** | .16** | -.00 | .05 |
| Paternal occupation | -.01 | -.01 | -.01 |
| Maternal occupation | .06 | -.07 | -.00 |
| Maternal education | -.03 | -.02 | .04 |
| Paternal education | -.06 | -.03 | -.03 |
| **Family income** | -.13** | -10* | -.03 |

**Correlation is sign. at a 0.01 level, * correlation is sig. at a 0.05 level & variables with significant associations with stress, anxiety or depression was shown in bold type

In order to test this question, regression analyses were used to test the effect of IQ and BD on the dependent variables (maternal stress, anxiety, depression) after controlling for only the variables which were significant in maternal outcome, for the maternal stress (child age, gender, other disability, disability in family, polygamy and family income), for the maternal anxiety (child age, other disability, disability in family, and family income) and for maternal depression (child age, gender and disability in family). Table 66 shows the effect of IQ and BD on maternal well-being after controlling for the demographic characteristics. The results revealed a strong and significant effect of the BD on all maternal well-being variables, whereas only maternal stress and anxiety were significantly predicted by IQ. Therefore, BD was used as a predictor in all further analysis in order to answer the study questions because it is always the one which predicts all maternal outcomes (stress, anxiety and depression). However, IQ was included as an additional control variable in exploratory analysis of maternal stress and anxiety, but not maternal depression, at the end of this chapter, although IQ did emerge as a significant prediction in Table 66, its relationship with maternal well-being are very much less than those of Behavioural Disorders (BD).

Table 66: The effect of IQ and BD on maternal well-being (stress, anxiety and depression) after controlling for child, mother and family characteristics

| | Variables | **Stress** | | **Anxiety** | | **Depression** | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.18 | .00 | -.15 | .00 | -.10 | .02 |
| | Child gender | -.15 | .00 | - | - | -.14 | .00 |
| | Other disability | -.08 | .07 | -.04 | .35 | - | - |
| | Disability in family | -.19 | .00 | -.12 | .01 | -.12 | .00 |
| | Polygamy | .16 | .00 | - | - | - | - |
| | Family income | -.11 | .02 | -.09 | .05 | - | - |
| 2 | Child age | -.08 | .00 | -.07 | .09 | .01 | .63 |
| | Child gender | -.17 | .00 | - | - | -.13 | .00 |
| | Other disability | -.04 | .11 | -.02 | .54 | - | - |
| | Disability in family | -.01 | .68 | -.02 | .63 | -.00 | .83 |
| | Polygamy | .02 | .45 | - | - | - | - |
| | Family income | .01 | .63 | -.01 | .80 | - | - |
| | IQ | -.06 | .04 | -.12 | .00 | .04 | .21 |
| | BD | .75 | .00 | .49 | .00 | .60 | .00 |

**Question 2:** Are the links between child disability and maternal well-being (stress, anxiety, and depression) mediated by coping strategies and social support?

This step tested the effect of the different coping techniques and different types of social support according to the factors resulting from the factor analyses in Chapter 9. In order to answer the second question, regression analyses were used to test the relationship between the primary dependent variables, the BD and maternal well-being (stress and anxiety and depression), along with the mediating effects of coping strategies and social support, after controlling for the characteristics of family and child (Baron & Kenny, 1986; Holmbeck, 1997). Initially we tested the model which was presented in Chapter 4 to test the hypotheses of the study. The mediating effects of all the variables were examined for each set of variables separately (see Figure 14) which means firstly the three coping strategies were examined in an independent regression analysis. Then three social support categories were examined in the second regression analysis.

Figure 14: Model of coping strategies and social support as mediators of the effect of behavioural disorders on maternal well-being

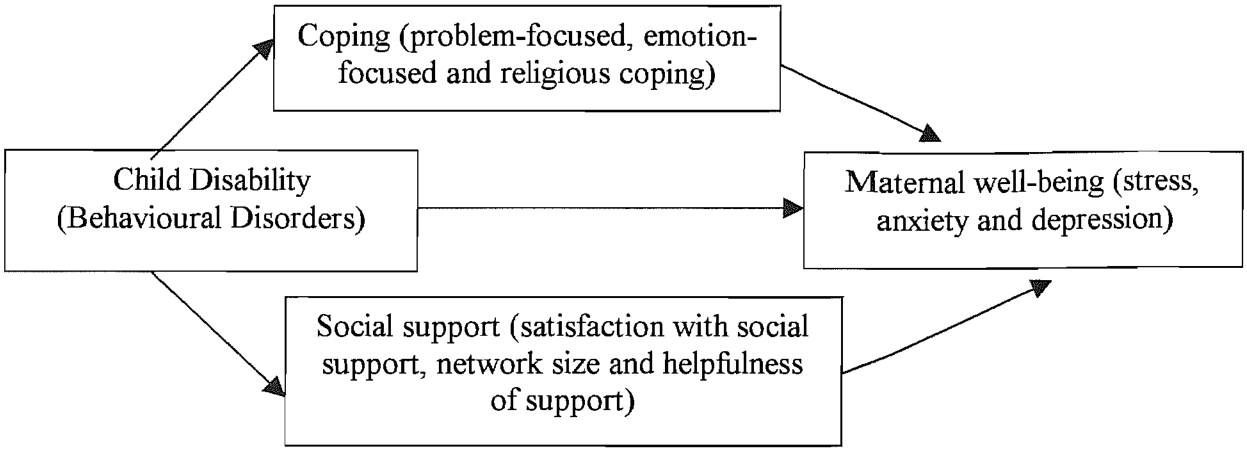


Figure 14 shows the mediating effect of the coping strategies and social support used by mothers of children with ID on maternal well-being (stress, anxiety and depression).

Table 67 shows that problem-focused coping has a direct effect on maternal well-being (stress, anxiety and depression). It seems to be acting as a compensatory variable, being associated with better maternal adjustment that showed by mothers who used a higher level of problem-focused coping. Emotion-focused coping also directly positively related to maternal stress. This means that use of emotion-focused coping is related to a higher level of maternal stress. Religious coping has a direct effect only on maternal anxiety. A low level of stress was shown by mothers who used a high level of religious coping. There is no evidence that coping acts as a mediator in the relationship between BD and maternal well-being (stress, anxiety and depression) and all of the coping strategies acted as compensatory variables which means they have direct effect on maternal outcome. Although Beta for the BD at Step 3 of the analysis were reduced very slightly, there are still very strong and highly significant effects for BD as a predictor.

Table 67: Testing the mediating effect of coping strategies

| | Variables | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.19 | .00 | -.16 | .00 | -.11 | .02 |
| | Child gender | -.14 | .00 | - | - | -.14 | .00 |
| | Other disability | -.08 | .10 | -.02 | .60 | - | - |
| | Disability in family | -.19 | .00 | -.12 | .01 | -.13 | .00 |
| | Polygamy | .16 | .00 | - | - | - | - |
| | Family income | -.12 | .01 | -.10 | .05 | - | - |
| 2 | Child age | -.09 | .00 | -.09 | .03 | -.01 | .65 |
| | Child gender | -.15 | .00 | - | - | -.14 | .00 |
| | Other disability | -.05 | .09 | -.01 | .78 | - | - |
| | Disability in family | -.00 | .79 | .01 | .75 | -.01 | .75 |
| | Polygamy | .02 | .43 | - | - | - | - |
| | Family income | -.00 | .94 | -.00 | .97 | - | - |
| | BD | .77 | .00 | .53 | .00 | .58 | .00 |
| 3 | Child age | -.10 | .00 | -.09 | .03 | -.02 | .57 |
| | Child gender | -.14 | .00 | - | - | -.14 | .00 |
| | Other disability | -.05 | .06 | -.01 | .67 | - | - |
| | Disability in family | .00 | .98 | .00 | .83 | -.00 | .98 |
| | Polygamy | .02 | .36 | - | - | - | - |
| | Family income | -.00 | .90 | -.00 | .91 | - | - |
| | BD | .74 | .00 | .48 | .00 | .56 | .00 |
| | Problem-focused | -.14 | .00 | -.12 | .03 | -.16 | .00 |
| | Emotion-focused | .09 | .02 | .04 | .44 | .04 | .39 |
| | Religious coping | -.00 | .79 | -.11 | .01 | .02 | .57 |

Table 68 shows the results of the regression analysis to test the mediating effect of social support on maternal outcome. Satisfaction with support (SPS) and helpfulness of support (FSS) had a significant direct effect on maternal stress. Moreover , helpfulness of support (FSS ) and size of support network (FSS2) significantly predict maternal depression, which means the higher the helpfulness of support is related with lower level of maternal stress and depression and the more sources of support available, the higher depression scores, which might be related to living with high number of members in extended family who are not supported might negatively leads to more depression. It is worth mentioning that social support (SPS, FSS, and FSS2) did not show any significant mediating results on maternal well-being (stress, anxiety and depression) but they played compensatory variables role with direct effect on maternal stress and depression.

Table 68: Testing the mediating effect of social support

| | | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.18 | .00 | -.14 | .01 | -.07 | .21 |
| | Child gender | -.15 | .00 | - | - | -.13 | .01 |
| | Other disability | -.09 | .09 | -.08 | .16 | - | - |
| | Disability in family | -.18 | .00 | -.07 | .19 | -.14 | .01 |
| | Polygamy | .15 | .01 | - | - | - | - |
| | Family income | -.07 | .20 | -.04 | .43 | - | - |
| 2 | Child age | -.10 | .00 | -.09 | .06 | .00 | .92 |
| | Child gender | -.16 | .00 | - | - | -.13 | .00 |
| | Other disability | -.06 | .07 | -.05 | .25 | - | |
| | Disability in family | -.01 | .77 | .02 | .61 | -.03 | .47 |
| | Polygamy | -.01 | .70 | - | - | - | - |
| | Family income | .00 | .87 | .02 | .68 | - | - |
| | BD | .77 | .00 | .50 | .00 | .57 | .00 |
| 3 | Child age | -.10 | .00 | -.10 | .05 | .00 | .94 |
| | Child gender | -.15 | .00 | - | - | -.12 | .00 |
| | Other disability | -.04 | .20 | -.04 | .35 | - | - |
| | Disability in family | -.01 | .74 | .02 | .60 | -.02 | .55 |
| | Polygamy | -.01 | .71 | - | - | - | - |
| | Family income | .01 | .70 | .02 | .64 | - | - |
| | BD | .71 | .00 | .47 | .00 | .54 | .00 |
| | SPS | -.12 | .00 | -.08 | .14 | -.08 | .09 |
| | FSS | -.14 | .02 | -.11 | .21 | -.18 | .03 |
| | FSS2 | .03 | .59 | .08 | .35 | .19 | .02 |

**Question 3:** Are the links between child BD and maternal well-being (stress, anxiety and depression) moderated by coping strategies, social support and family structure?

In order to answer the third question, multiple regression analyses were used to test the relationship between the primary dependent variables, the child's BD and maternal well-being (stress, anxiety and depression), along with the moderating effects of coping, social support, family structure, after controlling for the characteristics of family and child (Baron & Kenny, 1986; Holmbeck, 1997). Initially we tested the model which was presented in Chapter 4 to test the hypotheses of the study. The moderating effects of all the variables were examined for each variable separately. Interactions for the main regression analyses were derived from the product of the z-transformed scores of the relevant predictor variables. The interaction parameter was transformed using a centring procedure that removes possible confounds between interactions and the main effects in the regression models (Aiken & West, 1991). In case of significant interaction between ID and any of the moderators and in order to explore the nature of these interaction effects, data plots were based on the guidelines developed by Aiken and West (1991). Figures 16, 17 and 18 show the predicted values derived from the regression equations for the religious coping strategy, emotion-focused coping and social support (one SD below the mean, at the mean value, and one SD above the mean) all of the results were compared between the two groups (mothers of children with high BD, and mothers of children with low BD) to identify any differences in the outcomes for the mothers. This step aimed to test the moderation effect of the various coping techniques and different types of social support and family structure.

In order to test the effect of different types of coping strategies, social support and family structure on maternal well-being (stress, anxiety and depression) multiple regressions were tested for the coping strategies (problem-focused coping, emotion-focused coping and religious coping), social support (satisfaction of support, helpfulness of social support and network size) and family structure (extended and nuclear).

In order to test the moderating effects of coping strategies, social support, and family structure between child BD and maternal well-being, results were categorized by different maternal outcomes. Hence, results were presented of the effect of coping, social support, and family structure between child BD and maternal stress, anxiety and depression independently.

Figure 15: Model of coping, social support and family structure moderation of the effect of child behavioural disorders on maternal well-being

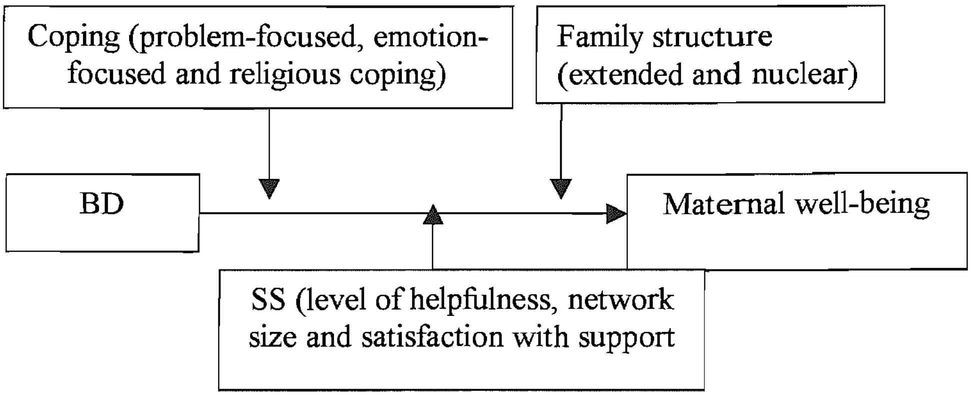


Table 69 shows a significant moderation effect of religious coping on the relation between BD and maternal stress and anxiety, but not depression. Moreover, emotion-focused coping showed a near to significant level (P=.05) on maternal anxiety. It is worth mentioning that problem-focused coping did not show any significant moderating effect on maternal well-being (stress, anxiety and depression).

Table 69: The moderating effect of coping strategies

| | | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.19 | .00 | -.16 | .00 | -.11 | .02 |
| | Child gender | -.14 | .00 | - | - | -.14 | .00 |
| | Other disability | -.08 | .10 | -.02 | .60 | - | - |
| | Disability in family | -.19 | .00 | -.12 | .01 | -.13 | .00 |
| | Polygamy | .16 | .00 | - | - | - | - |
| | Family income | -.12 | .01 | -.10 | .05 | - | - |
| 2 | Child age | -.09 | .00 | -.09 | .03 | -.01 | .65 |
| | Child gender | -.15 | .00 | - | - | -.14 | .00 |
| | Other disability | -.05 | .09 | -.01 | .78 | - | - |
| | Disability in family | -.00 | .79 | -.01 | .75 | -.01 | .75 |
| | Polygamy | .02 | .43 | - | - | - | - |
| | Family income | .00 | .94 | -.00 | .97 | - | - |
| | BD | .77 | .00 | .53 | .00 | .58 | .00 |
| 3 | Child age | -.10 | .00 | -.09 | .02 | -.02 | .53 |
| | Child gender | -.14 | .00 | - | - | -.14 | .00 |
| | Other disability | -.07 | .02 | -.03 | .42 | - | - |
| | Disability in family | .00 | .86 | .00 | .97 | .00 | .90 |
| | Polygamy | .03 | .34 | - | - | - | - |
| | Family income | .00 | .90 | -.00 | .88 | - | - |
| | BD | -.05 | .84 | -.54 | .15 | -.07 | .82 |
| | Problem-focused coping | -.13 | .00 | -.10 | .05 | -.15 | .00 |
| | Emotion-focused coping | .11 | .00 | -.08 | .15 | .06 | .22 |
| | Religious coping | -.03 | .28 | -.15 | .00 | -.00 | .94 |
| | BD*Problem-focused | .17 | .37 | -.11 | .66 | .15 | .54 |
| | BD*Emotion-focused | .05 | .69 | .34 | .05 | .07 | .64 |
| | BD*Religious coping | .59 | .04 | .82 | .04 | .04 | .27 |

Regarding Aiken and West (1991), in the case of significant interaction between ID and any of the moderators and in order to explore the nature of these interaction effects, data plots were required as a further step in order to explain the interaction. It is worth mentioning here that when the participants' answers were recoded (one SD below the mean, at the mean value, and one SD above the mean) only the first two levels of religious coping were shown in the results. Whereas no response was reported in the "one SD above the Mean". Figure 16 shows that in the case of having children with ID, mothers who showed a high level of maternal stress tended to focus more on religious coping, whereas mothers who experienced a low level of maternal stress did not.

When two groups of mothers were compared, mothers of children with low and high BD, results revealed that in the case of low BD, mothers who used more religious coping showed a lower level of stress. Whereas, where there was a high level of BD which led to a high level of maternal stress, those mothers who showed the highest level of stress tended to use more religious coping than others.

Figure 16: Interpretation of the interaction effect of BD and religious coping on maternal stress.

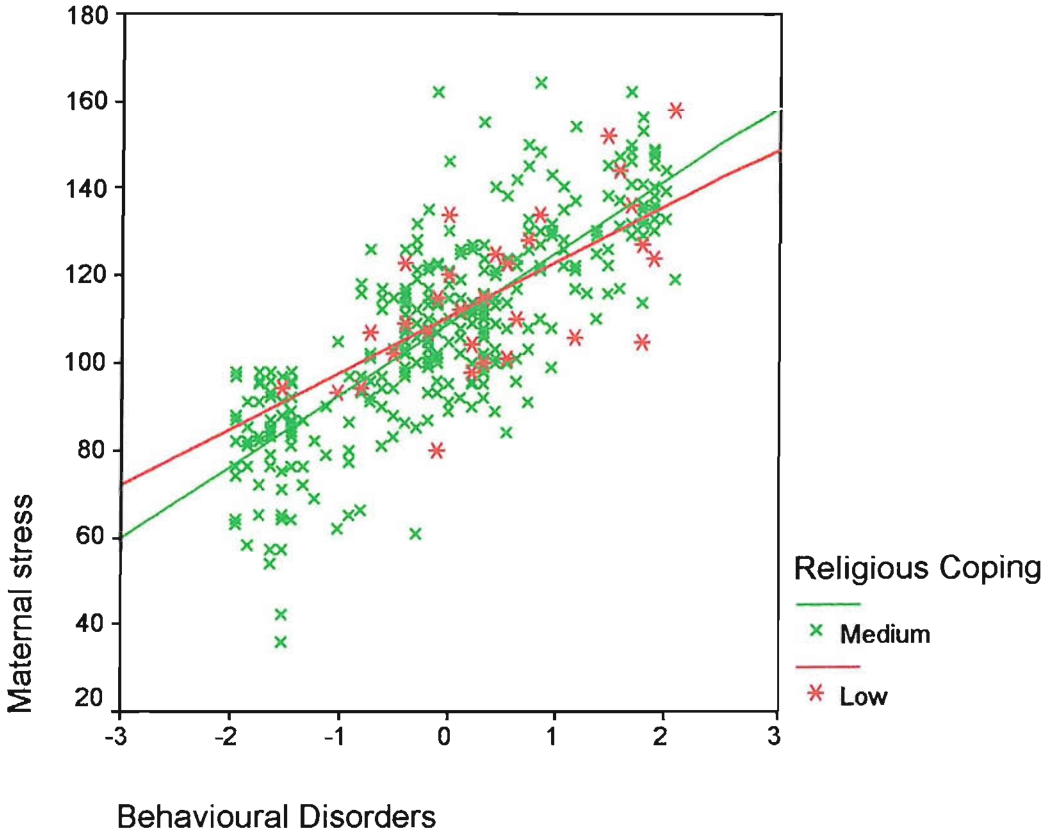


Figure 17 shows that when religious coping is low, maternal anxiety does not vary strongly with the child's behavioural disorders (BD), but when religious coping is medium, mothers with children who have high levels of

BD report more anxiety. This result is similar to what was reported regarding the relation between stress and religious coping (Figure 16) when there was a high level of BD which led to a high level of maternal stress or anxiety, those mothers who showed the highest level of stress or anxiety tended to use more religious coping than others.

Figure 17: Interpretation of the interaction effect of BD and religious coping on maternal anxiety

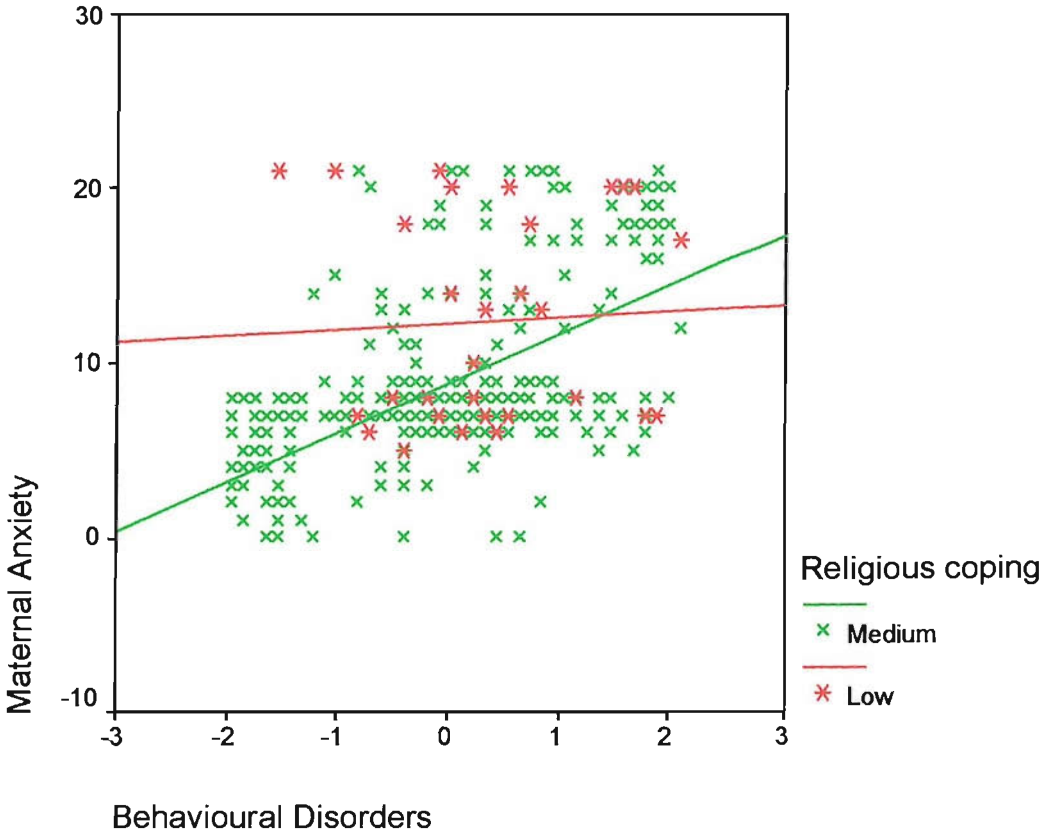


Figure 18 illustrates a positive moderation effect, the more the mothers used emotion-focused coping the higher their level of anxiety. When the three groups were analysed independently (low, medium and high), when the emotion-focused coping is low, maternal anxiety does not vary strongly with child's BD, but when the using of emotion-focused coping is medium or high, mothers with children who have high levels of BD report more anxiety symptoms.

Figure 18: Interpretation of the interaction effect of BD and emotion-focused coping on maternal anxiety.

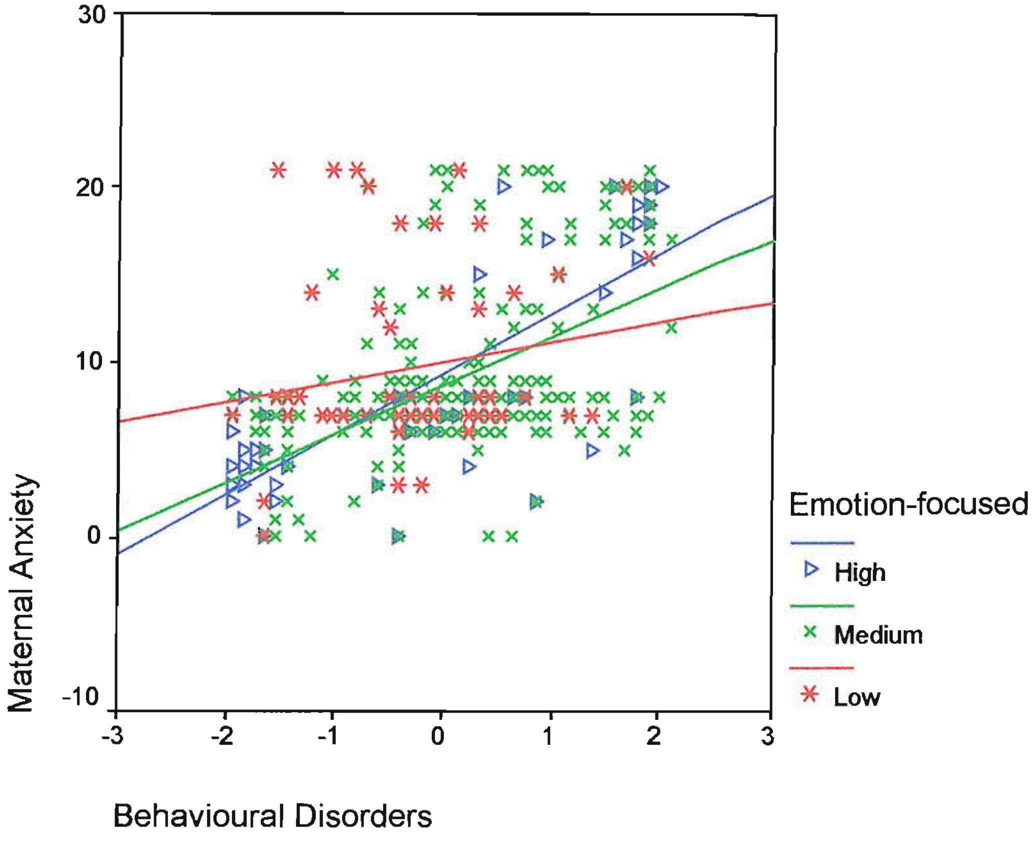


Table 70 shows that there was no significant moderation effect of any type of social support on stress, anxiety and depression. However, only satisfaction with social support (SPS) showed a near to significant moderation effect on anxiety (p=.07).

Table 70: The moderating effect of social support

| | | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.18 | .00 | -.14 | .01 | -.07 | .21 |
| | Child gender | -.15 | .00 | - | - | -.13 | .01 |
| | Other disability | -.09 | .09 | -.08 | .16 | - | - |
| | Disability in family | -.18 | .00 | -.07 | .19 | -.14 | .01 |
| | Polygamy | .15 | .01 | - | - | - | - |
| | Family income | -.07 | .20 | -.04 | .43 | - | - |
| 2 | Child age | -.10 | .00 | -.09 | .06 | .00 | .92 |
| | Child gender | -.16 | .00 | - | - | -.13 | .00 |
| | Other disability | -.06 | .07 | -.05 | .25 | - | - |
| | Disability in family | -.01 | .77 | .02 | .61 | -.03 | .47 |
| | Polygamy | -.01 | .70 | - | - | - | - |
| | Family income | .00 | .87 | -.02 | .68 | - | - |
| | BD | .77 | .00 | .50 | .00 | .57 | .00 |
| 3 | Child age | -.10 | .00 | -.09 | .08 | .00 | .90 |
| | Child gender | -.15 | .00 | - | - | -.12 | .00 |
| | Other disability | -.04 | .19 | -.05 | .30 | - | |
| | Disability in family | -.01 | .74 | .02 | .67 | -.03 | .53 |
| | Polygamy | -.01 | .66 | - | - | - | - |
| | Family income | .01 | .75 | .00 | .86 | - | - |
| | BD | .71 | .00 | .46 | .00 | .54 | .00 |
| | SPS | -.12 | .00 | -.08 | .12 | -.08 | .08 |
| | FSS | -.13 | .04 | -.13 | .16 | -.18 | .03 |
| | FSS2 | .03 | .58 | .10 | .26 | .18 | .02 |
| | BD*SPS | -.00 | .91 | -.09 | .07 | -.02 | .56 |
| | BD*FSS | .05 | .49 | .03 | .77 | -.06 | .52 |
| | BD*FSS2 | -.04 | .58 | -.04 | .64 | .06 | .48 |

It was proved in Table 71 that family structure has a direct effect on stress with a lower level of maternal stress reported by mothers who live in extended families. However, Table 71 does not show any significant moderation effect of the family structure (extended and nuclear) on all maternal outcomes (stress, anxiety and depression).

Table 71: The moderating effect of family structure

| | | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.19 | .00 | -.15 | .00 | -.10 | .02 |
| | Child gender | -.16 | .00 | - | - | -.15 | .00 |
| | Other disability | -.08 | .07 | -.04 | .32 | - | - |
| | Disability in family | -.18 | .00 | -.11 | .02 | -.11 | .01 |
| | Polygamy | .15 | .00 | - | - | - | - |
| | Family income | -.12 | .01 | -.10 | .04 | - | - |
| 2 | Child age | -.09 | .00 | -.08 | .05 | -.01 | .64 |
| | Child gender | -.16 | .00 | - | - | -.14 | .00 |
| | Other disability | -.04 | .13 | -.02 | .53 | - | - |
| | Disability in family | -.00 | .87 | .00 | . 93 | -.00 | .83 |
| | Polygamy | .02 | .51 | - | - | - | - |
| | Family income | .01 | .67 | -.01 | .66 | - | - |
| | BD | .76 | .00 | .52 | .00 | .58 | .00 |
| 3 | Child age | -.10 | .00 | -.08 | .05 | -.01 | .70 |
| | Child gender | -.16 | .00 | - | - | -.14 | .00 |
| | Other disability | -.04 | .13 | -.02 | .51 | - | - |
| | Disability in family | -.01 | .60 | .00 | .99 | -.00 | .86 |
| | Polygamy | .02 | .49 | - | - | - | - |
| | Family income | .00 | .87 | -.02 | .62 | - | - |
| | BD | .74 | .00 | .52 | .00 | .59 | .00 |
| | Family structure | .09 | .00 | -.02 | .50 | -.03 | .38 |
| | BD*family structure | -.01 | .55 | .01 | .72 | -.05 | .17 |

## **10.5. Conclusion:**

The present chapter attempted to explore to what extent the different levels of ID were related to maternal well-being (stress, anxiety and depression). Generally, the findings confirmed the usefulness of testing the differences between IQ and BD as integral parts of ID. Behavioural disorders was found to be a stronger predictor for all the dependent variables (stress, anxiety and depression), whereas IQ significantly predicted maternal stress and anxiety only when controlled for child and family characteristics.

Overall, the current results led to several findings that departed from the study hypotheses, while a couple of findings were consistent with our prediction in the study model (Figure 11, Chapter 4). Firstly, results revealed significant correlations of child age and disability in another family member with all maternal outcomes (stress, anxiety and depression). Child gender significantly correlated only with maternal stress and depression. Other disability and family income significantly correlated with maternal stress and anxiety. Polygamy only correlated significantly with maternal stress.

The results also revealed that some of the child and family characteristics showed a significant negative effect and some showed a positive effect. Child age, gender, other disability, disability in another family member, polygamy and family income had a significant direct effect on maternal stress. Mothers of younger males, with lower income who lived in polygamous families and who had more than one disabled member within their families showed a higher level of stress.

Only child age, family income, other disability, and having more than one disabled family member showed a significant direct effect on maternal anxiety. Mothers of younger children who have more than one disability, with a lower income and more than one disabled member living with them showed high levels of anxiety.

Age, gender, and disability in another family member showed a direct effect on the level of maternal depression. Mothers of younger male children who had another disabled member within their family showed more depression symptoms.

Finally, the relation between child BD and different maternal outcomes (stress, anxiety and depression) showed some moderating results. To summarize all the mediating and moderating results addressed in this chapter, Table 72 concluded all significant and insignificant results of coping strategies, social support and family structure on maternal well-being as follows:

Table 72: Conclusion of the results

| | Stress | | Anxiety | | Depression | |
|---|---|---|---|---|---|---|
| | Med. | Mod. | Med. | Mod. | Med. | Mod. |
| Emotion-focused coping | x | x | x | *ns | x | x |
| Problem-focused coping | x | x | x | x | x | x |
| Religious coping | x | ✓ | x | ✓ | x | x |
| Satisfaction with social support | x | x | x | *ns | x | x |
| Network size | x | x | x | x | x | x |
| Helpfulness of social support | x | x | x | x | x | x |
| Family structure | - | x | - | x | - | x |

*ns: nearly significant (p=.05 & .07)

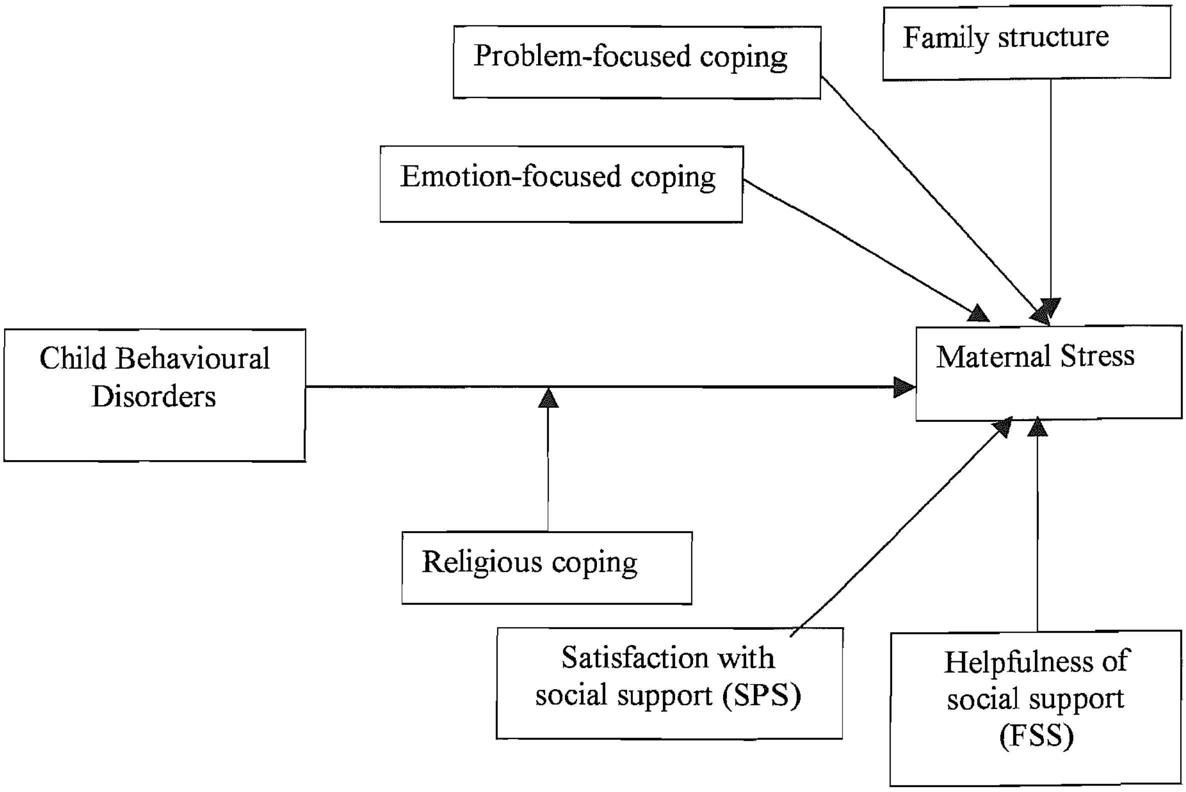
The results of this study expanded the hypothesised model presented in Figure 11 (Chapter 4). Maternal well-being was divided into three different models of maternal stress, maternal anxiety and maternal depression. Regarding the first model (Figure 19), after controlling for some of the child and family characteristics (child age, gender, other disabilities, disability in another family member, polygamy) the results showed a strong effect of child BD on maternal stress. Only one coping strategy, which was religious coping, showed a moderating role between child BD and maternal stress and between BD and maternal anxiety.

The results of the scatter plot explained that in the case of low BD, which led to a lower level of maternal stress, parents who used religious coping more showed the lowest stress level. However, in the case of high (severe) BD, which led to a higher level of maternal stress, mothers who showed a high level of stress tended to focus more on religious coping. Hence, they reported the highest use of religious coping.

Problem-focused coping and emotion-focused coping acted as compensatory variables; they showed a direct effect on maternal stress with no significant mediation or moderation effect between a child's BD and maternal stress. Religious coping showed a negative moderating effect between BD and maternal stress.

Regarding social support, only satisfaction with support (SPS) and helpfulness of support (FSS) showed a negative direct effect on maternal stress which means mothers who received a high level of social support showed a low level of stress. Network size (FSS2) did not show any significant effect on stress, anxiety or depression, which means that for mothers of ID children the amount of support was not as important as its helpfulness of or their satisfaction with it. Finally, family structure showed a direct positive effect on maternal stress, which means that mothers who lived within an extended family showed a lower level of stress than those lived in a nuclear family. However, family structure did not show any significant moderating role between disability and maternal well-being (stress, anxiety and depression).

Figure 19: The impact of coping, social support and family structure on maternal stress



The second model (Figure 20) derived from the main study model (Figure 11, Chapter 4) after controlling for some of the child and family characteristics (child age, other disabilities and disability in another family member), regression analysis showed a strongly significant effect of child BD on maternal anxiety. Religious coping showed a moderating effect between BD and maternal anxiety. Whereas, emotion-focused coping was near to significant level as a moderator between BD and maternal anxiety (.05).

When religious coping was low, maternal anxiety did not vary greatly with the child's behavioural disorders (BD), but when religious coping was high, mothers with children who had high levels of BD reported more anxiety.

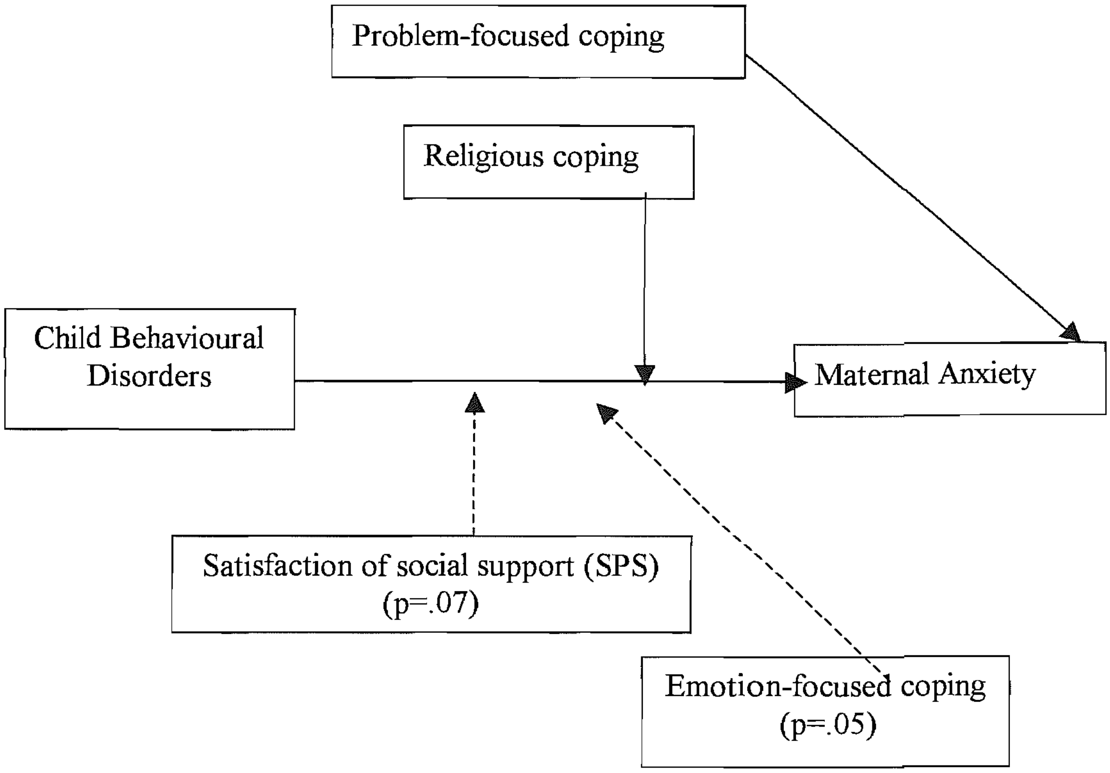
This result is similar to the relation between stress and religious coping, when there was a high level of BD which led to a high level of maternal anxiety, those mothers who showed the highest level of anxiety tended to use more religious coping than others.

The use of emotion-focused coping was near to significant level (.05) which showed a “nearly” positive moderating effect, the more the mothers used emotion-focused coping, the higher their level of anxiety. When the three groups (low, medium and high BD) were analysed independently, mothers who used a low level of emotion-focused coping did not vary greatly with child’s BD, but when emotion-focused coping was medium or high, mothers with children who had high levels of BD reported more anxiety.

There was a nearly significant moderating effect of satisfaction with social support (.07): the higher the level of maternal satisfaction, the lower the level of anxiety. These results showed that in case of high maternal anxiety did not vary strongly with child’s BD, but when the satisfaction with social support was low, mothers with children who had high levels of BD reported more anxiety.

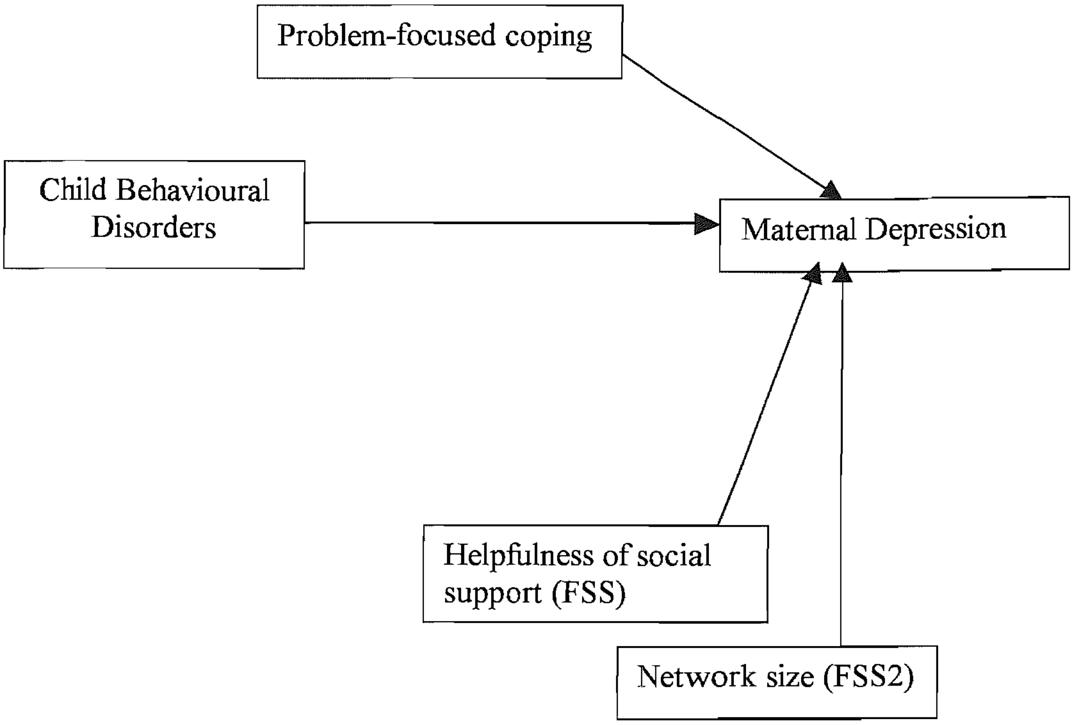
Helpfulness of social support (FSS), network size (FSS2) and family structure did not show any effect on maternal anxiety (see Figure 20).

Figure 20: The impact of coping and social support on maternal Anxiety



The third and last model (Figure 21) presented the relationship between child BD and maternal depression. After controlling for the child and family characteristics (child age, gender and disability in another family member), only problem-focused coping, helpfulness of social support (FSS) and support network size (FSS2) showed any direct effect on maternal depression and they acted as compensatory variables. It is worth mentioning that emotion-focused coping, religious coping, support satisfaction (SPS), and family structure did not show any significant results when used with the maternal depression regression test.

Figure 21: The impact of coping and social support on maternal depression



In conclusion, the child's Behavioural Disorders (BD) showed a very strong effect on maternal well-being, with a high level of stress, anxiety and depression shown by mothers of children who had a high level of BD. Although emotion-focused coping was nearly significant as a moderator between BD and maternal anxiety, problem-focused and emotion-focused coping showed direct effects on maternal well-being, but they did not show any mediating or moderating effect. Only religious coping had a significant moderating effect between the child's BD and maternal stress and anxiety.

Regarding social support, this has a direct effect on maternal well-being, however, it did not show any significant mediating or moderating effect. Only the satisfaction with social support (SPS) showed nearly significant results as a moderator between BD and maternal anxiety.

These results were different from what has been reported in the literature, where the focus was on the importance of the use of religious coping to those mothers which they might use instead of other coping strategies. Family structure and social support showed some effect on maternal well-being but they did not play their expected roles even as mediators or moderators, for many reasons which will be specified in Chapter 11.

## 10.6. Additional exploratory analyses:

As mentioned earlier in this chapter, IQ had a significant effect only on stress and anxiety. However, it was not included as a control variable in the previous analyses since BD showed a stronger significant effect on all maternal well-being outcomes (stress, anxiety and depression). The regression analyses, which have been presented earlier, used unified predictors, mediators ,moderators and outcomes. The last step of this chapter is an additional analysis. IQ was included as an additional variable in the analysis of maternal stress and anxiety in order to test the mediating and/or moderating effects of coping strategies, social support and family structure.

### 10.6.1. The mediation role of coping strategies and social support:

The results of Table 73 show that neither social support nor coping strategies showed any significant mediating effect on maternal stress and anxiety. However, problem-focused and emotion-focused coping showed a direct effect on maternal stress, along with religious coping, which showed a direct effect on maternal anxiety.

Regarding the social support mediating effect, Table 73 shows that only SPS and FSS had a direct effect on maternal stress and none of the social support categories had any significant mediation effect of any of the social support categories on maternal stress and anxiety.

Table 73: Testing the mediating effect of coping strategies and social support on maternal stress and anxiety

| | | Stress | | Anxiety | | | Stress | | Anxiety | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.19 | .00 | -.17 | .00 | Child age | -.18 | .00 | -.14 | .01 |
| | Child gender | -.13 | .00 | - | - | Child gender | -.14 | .01 | - | - |
| | Other disability | -.08 | .10 | -.02 | .58 | Other disability | -.10 | .09 | -.08 | .18 |
| | Disability in family | -.20 | .00 | -.14 | .00 | Disability in family | -.19 | .00 | -.08 | .15 |
| | Polygamy | .17 | .00 | - | - | Polygamy | .16 | .00 | - | - |
| | Family income | -.12 | .01 | -.09 | .07 | Family income | -.07 | .23 | -.04 | .52 |
| 2 | Child age | -.08 | .01 | -.09 | .04 | Child age | -.10 | .01 | -.08 | .10 |
| | Child gender | -.16 | .00 | - | - | Child gender | -.17 | .00 | - | - |
| | Other disability | -.05 | .07 | -.02 | .62 | Other disability | -.06 | .07 | -.05 | .29 |
| | Disability in family | -.01 | .61 | -.03 | .39 | Disability in family | -.02 | .59 | .00 | .98 |
| | Polygamy | .02 | .42 | - | - | Polygamy | -.01 | .66 | - | - |
| | Family income | -.00 | .97 | .01 | .73 | Family income | -.00 | .97 | .02 | .62 |
| | IQ | -.07 | .01 | -.13 | .00 | IQ | -.06 | .11 | -.13 | .01 |
| | BD | .75 | .00 | .50 | .00 | BD | .76 | .00 | .47 | .00 |
| 3 | Child age | -.09 | .00 | -.09 | .04 | Child age | -.09 | .00 | -.09 | .08 |
| | Child gender | -.15 | .00 | - | - | Child gender | -.15 | .00 | - | - |
| | Other disability | -.06 | .04 | -.02 | .56 | Other disability | -.04 | .22 | -.04 | .40 |
| | Disability in family | -.00 | .85 | -.03 | .42 | Disability in family | -.02 | .59 | .00 | .97 |
| | Polygamy | .02 | .38 | - | - | Polygamy | -.01 | .71 | - | - |
| | Family income | -.00 | .88 | .01 | .79 | Family income | .00 | .85 | .02 | .59 |
| | IQ | -.06 | .03 | -.12 | .00 | IQ | -.04 | .22 | -.13 | .01 |
| | BD | .73 | .00 | .47 | .00 | BD | .70 | .00 | .44 | .00 |
| | Problem-focused coping | -.15 | .00 | -.07 | .22 | SPS | -.12 | .00 | -.08 | .15 |
| | Emotion-focused coping | .09 | .02 | -.01 | .72 | FSS | -.14 | .03 | -.10 | .25 |
| | Religious coping | .00 | .96 | -.12 | .00 | FSS2 | .03 | .54 | .09 | .30 |

### 10.6. 2. The moderation role of coping strategies, social support and family structure:

Table 74 shows some significant interaction between coping strategies and child disability (BD and IQ). BD showed significant interaction with emotion-focused coping and religious coping, which means that emotion-focused and religious coping showed a moderating effect between child BD and maternal anxiety. While only religious coping showed a significant moderating effect between child IQ and maternal anxiety.

Regarding social support, none of the three social support categories showed any significant interaction between child BD and maternal anxiety. Only the support network size (FSS2) showed a significant moderating effect between child IQ and maternal stress. Whereas the helpfulness of social support was nearly significant (p=.06) as a moderator between child IQ and maternal stress.

Table 74: Testing the moderating effect of coping strategies and family support on maternal stress and anxiety

| | | Stress | | Anxiety | | | Stress | | Anxiety | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. | | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.19 | .00 | -.17 | .00 | Child age | -.18 | .00 | -.14 | .01 |
| | Child gender | -.13 | .00 | - | - | Child gender | -.14 | .01 | - | - |
| | Other disability | -.08 | .10 | -.02 | .58 | Other disability | -.10 | .09 | -.08 | .18 |
| | Disability in family | -.20 | .00 | -.14 | .00 | Disability in family | -.19 | .00 | -.08 | .15 |
| | Polygamy | .17 | .00 | - | - | Polygamy | .16 | .00 | - | - |
| | Family income | -.12 | .01 | -.09 | .07 | Family income | -.07 | .23 | -.04 | .52 |
| 2 | Child age | -.08 | .01 | -.09 | .04 | Child age | -.10 | .01 | -.08 | .10 |
| | Child gender | -.16 | .00 | - | - | Child gender | -.17 | .00 | - | - |
| | Other disability | -.05 | .07 | -.02 | .62 | Other disability | -.06 | .07 | -.05 | .29 |
| | Disability in family | -.01 | .61 | -.03 | .39 | Disability in family | -.02 | .59 | .00 | .98 |
| | Polygamy | .02 | .42 | - | - | Polygamy | -.01 | .66 | - | - |
| | Family income | -.00 | .97 | .01 | .73 | Family income | -.00 | .97 | .02 | .62 |
| | IQ | -.07 | .01 | -.13 | .00 | IQ | -.06 | .11 | -.13 | .01 |
| | BD | .75 | .00 | .50 | .00 | BD | .76 | .00 | .47 | .00 |
| 3 | Child age | -.10 | .00 | -.09 | .02 | Child age | -.09 | .01 | -.08 | .12 |
| | Child gender | -.15 | .00 | - | - | Child gender | -.15 | .00 | - | - |
| | Other disability | .07 | .02 | -.04 | .35 | Other disability | -.05 | .16 | -.04 | .39 |
| | Disability in family | .00 | .94 | -.02 | . 60 | Disability in family | -.02 | .46 | .00 | .98 |
| | Polygamy | .03 | .31 | - | - | Polygamy | -.00 | .94 | - | - |
| | Family income | .00 | .93 | .02 | .60 | Family income | .00 | .99 | .01 | .76 |
| | IQ | -.06 | .05 | -.11 | .00 | IQ | -.05 | .15 | -.12 | .02 |
| | BD | .03 | .90 | -.72 | .06 | BD | .70 | .00 | .43 | .00 |
| | Problem-focused | -.14 | .00 | -.05 | .34 | SPS | -.12 | .00 | -.09 | .11 |
| | Emotion-focused | .11 | .00 | .05 | .37 | FSS | -.13 | .04 | -.12 | .20 |
| | Religious coping | -.01 | .69 | -.14 | .00 | NEWFSS | .03 | .54 | .10 | .26 |
| | IQ*problem-focused | -.01 | .78 | .00 | .88 | IQ*ZSPS | -.03 | .44 | -.05 | .64 |
| | IQ*emotion-focused | -.00 | .87 | .04 | .44 | IQ*FSS | .15 | .06 | .09 | .11 |
| | IQ*religious coping | .04 | .15 | .09 | .03 | IQ*FSS2 | -.16 | .04 | .00 | .99 |
| | BD*problem-focused | .22 | .28 | -.13 | .63 | BD*SPS | -.00 | .83 | -.06 | .26 |
| | BD*emotion-focused | .01 | .93 | .38 | .04 | BD*FSS | .08 | .30 | .01 | .89 |
| | BD*religious coping | .47 | .10 | .98 | .01 | BD*FSS2 | -.07 | .36 | -.02 | .84 |

As mentioned earlier, in the case of significant interaction between Intellectual Disability (ID) and any of the moderators and in order to explore the nature of these interaction effects, data plots were investigated as further analysis. The interaction of BD and emotion-focused and the interaction of BD and religious coping were mentioned earlier in Figures (17 and 18).

Figure 22 shows the moderating effect of religious coping between child IQ and maternal anxiety. The results in Figure 22 show that when mothers used a medium level of religious coping, maternal anxiety did not vary greatly with child's IQ, but when the use of religious coping is low, mothers of children who have low level of IQ report more anxiety symptoms.

Figure 22: Iinterpretation of the interaction effect of IQ and religious coping on maternal anxiety.

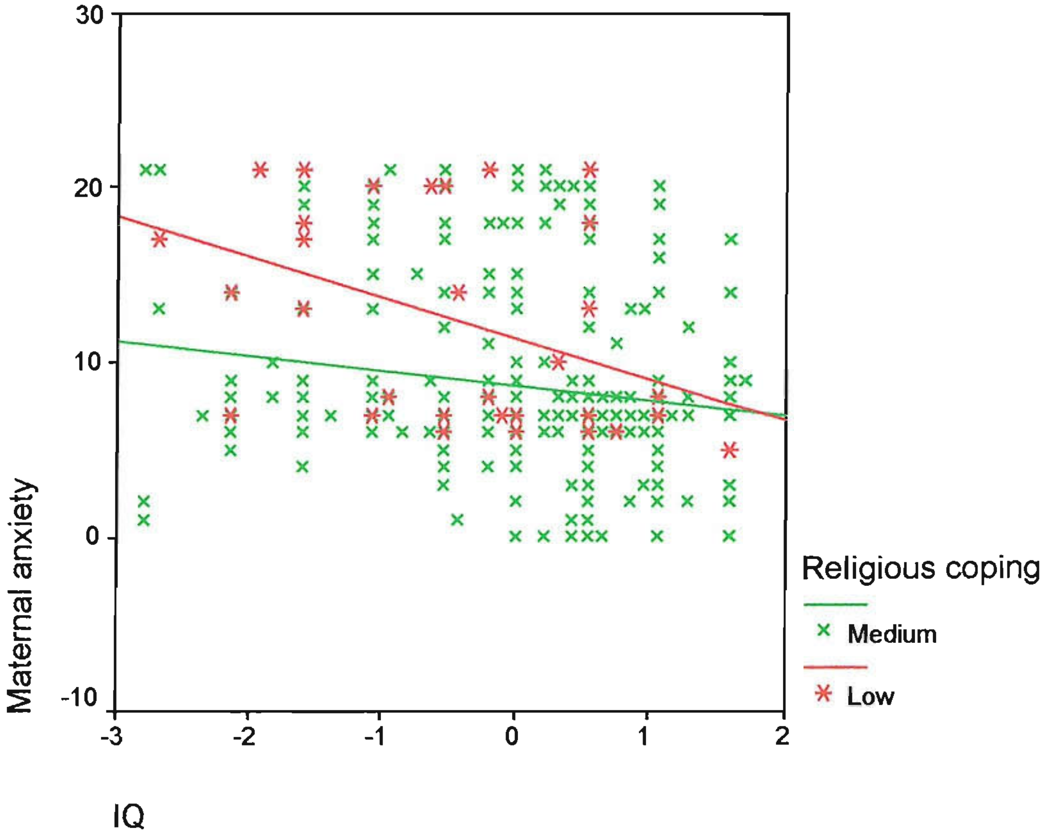
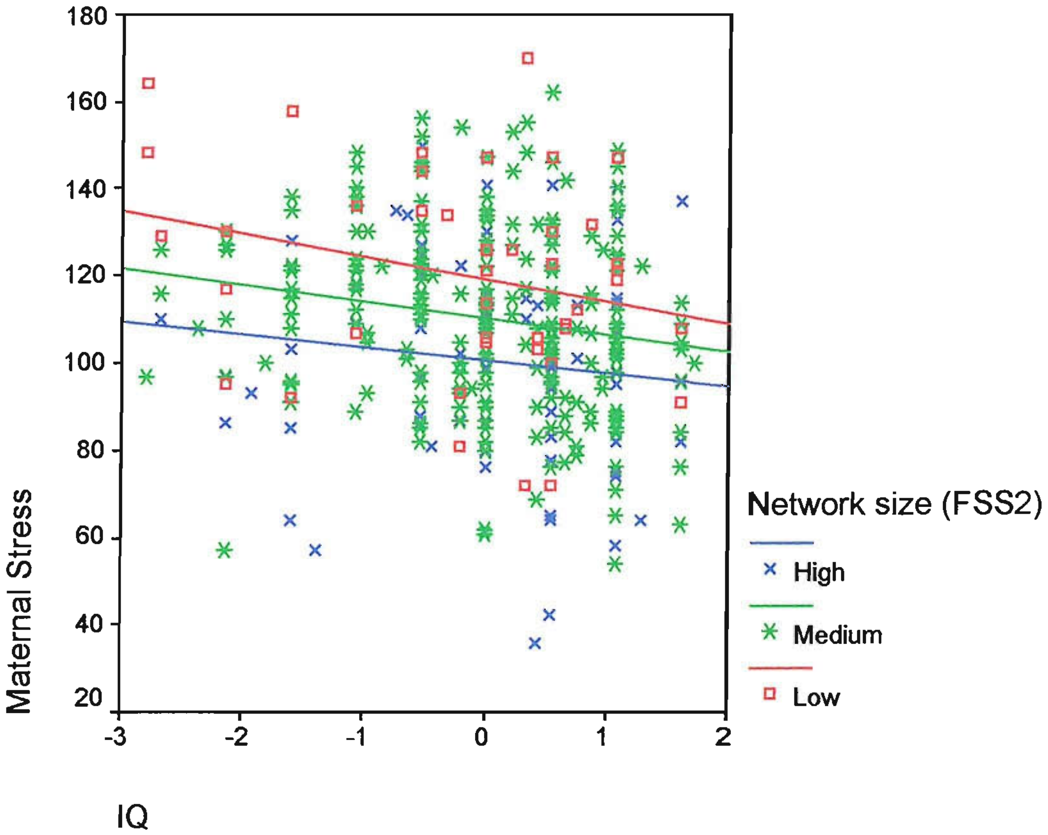


Figure 23 shows the moderating effect of the support network size (FSS2) between child IQ and maternal stress. The results in Figure 23 show that mothers who have the benefit of a high number of social support resources show a low level of stress than those who have few social support resources, who report high levels of stress.

Figure 23: Interpretation of the interaction effect of IQ and support network size (FSS2) on maternal anxiety.



Finally, family structure did not show any significant moderating effect on maternal stress and anxiety. (Table 75).

Table 75: Testing the moderating effect of family structure on maternal stress and anxiety

| | | Stress | | Anxiety | |
|---|---|---|---|---|---|
| | | Beta | Sig. | Beta | Sig. |
| 1 | Child age | -.18 | .00 | -.15 | .00 |
| | Child gender | -.15 | .00 | - | - |
| | Other disability | -.08 | .07 | -.04 | .36 |
| | Disability in family | -.19 | .00 | -.12 | .01 |
| | Polygamy | .16 | .00 | - | - |
| | Family income | -.11 | .02 | -.09 | .05 |
| 2 | Child age | -.08 | .00 | -.07 | .10 |
| | Child gender | -.17 | .00 | - | - |
| | Other disability | -.04 | .11 | -.02 | .55 |
| | Disability in family | -.01 | .69 | -.02 | .64 |
| | Polygamy | .02 | .48 | - | - |
| | Family income | -.01 | .63 | -.01 | .79 |
| | IQ | -.06 | .05 | -.13 | .00 |
| | BD | .75 | .00 | .49 | .00 |
| 3 | Child age | -.09 | .00 | -.06 | .11 |
| | Child gender | -.17 | .00 | - | - |
| | Other disability | -.04 | .12 | -.02 | .51 |
| | Disability in family | -.02 | .45 | -.01 | .71 |
| | Polygamy | .02 | .50 | - | - |
| | Family income | -.00 | .80 | -.01 | .74 |
| | IQ | -.08 | .50 | -.25 | .15 |
| | BD | .73 | .00 | .50 | .00 |
| | Family structure | .10 | .00 | -.04 | .31 |
| | IQ*family structure | -.13 | .26 | .12 | .49 |
| | BD*family structure | -.02 | .44 | .02 | .54 |

The previous exploratory analyses, when IQ was included as an additional variable to the analysis of maternal stress and anxiety, did not show any significant effect of all hypothesised mediators. However, only religious coping showed a moderating effect between child disability (IQ and BD) and maternal anxiety. Emotion-focused coping moderated the relation between BD and maternal anxiety. Regarding social support, only the support network size (FSS2) was a significant moderator between IQ and maternal stress, where the helpfulness of social support (FSS1) was near to significant (p=.06) as a moderator between IQ and maternal stress.

Even some of the significant results which are shown in tables 67 to 71, when the BD was the only predictor, lost their significance when IQ was controlled for. This might be because the Stanford- Binet intelligence results were collected from the children's files moreover, when the reliability and validity of all questionnaires were tested, this test was not included. More explanation of the insignificant relation of IQ and other variables will be presented in Chapter 11.

# CHAPTER 11

# GENERAL DISCUSSION

One of the theoretical interests of this thesis was to present an idea of the similarities and differences between mothers with and without children with ID in the outcomes for families. Moreover, the thesis examined the relationship between child ID and coping strategies/social support/ family structure and maternal well-being in mothers of ID children. The purpose of this last chapter is to summarise the findings of the empirical work conducted within this thesis in order to consider the implications of the findings for mothers of children with ID and to discuss the theoretical and conceptual issues involved.

The three main questions of the study were:

1. Does child IQ or BD predict maternal well-being (stress, anxiety and depression) after controlling for other factors?
2. Are the links between child disability and maternal well-being (stress, anxiety, and depression) mediated by coping and social support?
3. Are the links between child disability and maternal well-being moderated by coping, social support and family structure?

In order to answer these questions, it was important to assess the psychometric data of the measures (PSI-SF, Brief COPE, SPS, FSS, and the HADS) of mothers of children with and without ID. Hence, the research was conducted in three stages in order to find the psychometric data of all the measures. The first stage (Study 1) focused on interviewing mothers in order to explore their beliefs and ideas about their situation, their children, their family and the questionnaire items that were used. The results from the first study led us to the second stage of the research (Study 2). The translation of all the scales was the objective of the second stage. All the scales were examined using Vallerand's methodology in cross-cultural psychology (Vallerand, 2000). The results revealed significant levels of reliability and validity of all translated questionnaires, in addition to the modified and added items. This led to the third stage (Study 3), which focused on the new factor structure of all Arabic instruments and finding the differences in mean scores for all scales between Saudi and western families of TD and ID children. Differences between Saudi mothers with and without ID children recruited in this study were also reported. This third stage led us to the main study (Study 4), which focused upon testing the models of disability and maternal well-being mediated by coping strategies and social support and moderated by coping strategies, social support and family structure.

The current chapter shows how the results of the studies help to address the three main questions of the thesis. In addition, the limitations of study design and procedures are discussed. Finally, suggestions for future research are discussed.

## 11.1. Results:

### Study 1 (Interviewing mothers):

Until recently, cultural issues in the perception and measurement of psychopathology received little attention, due to the influence of the universalist approach (Marsella & Kameoka, 1989). Psychological disorders may vary in degree, diagnostic patterns and expression across different cultures (Reid, 1995) and this universality has been examined by some authors who claim that culture can play an important role in psychopathology by determining standards of normality and abnormality (Reid, 1995). The aim of this stage of the thesis was to present the explanation of those mothers' perceptions, dealing with their disabled children, their perception of the social support they received and their mental health status. The other importance of this study was to assess the mothers' point of view about measures that were translated in later steps.

The results of this stage showed that mothers of ID children preferred to live within a modified extended family rather than the original extended family or nuclear family. Husbands and parents were reported to be the most useful source of support. Emotion-focused coping and problem-focused coping have been reported to be used at different levels by all the mothers. At the same time, concern about the future was reported to place a great deal of stress upon many mothers which makes most of them report their mental state as highly anxious and sometimes depressed. The most important result of this study was an unanimity of perceptions that religion determines mothers' concept of coping and the support they received. This had implications for the measurement of coping, although the remainder of constructs seemed to be viewed in a similar way to a western sample, although emphases would undoubtedly be different.

### Study 2 (Translation Process):

One of the central aims of the present thesis was to develop assessment tools that would form valid and reliable measures to identify and quantify Saudi mothers' stress, coping, social support, and mental health.

After following the seven main steps of Valleran's methodology of cross-cultural translation, findings of this study showed that the adapted versions of the PSI-SF, Brief COPE, SPS, FSS, and HADS administered in a normative Saudi sample had achieved satisfactory validity and reliability in terms of the total scales and sub-scales. Even the two added items and the modified 'substance use' items in the Brief COPE, in addition to modified items in PSI-SF and item '9' in HADS, showed high levels of reliability and validity. However, only two of the Brief COPE subscales 'acceptance' and 'venting' had a low, but still acceptable, level of internal consistency which was also a low internal consistency in the original study (Carver, 1997) and that was probably because of the small number of items in each subscale (two items).

**Study 3 (Introductory step to the main study):**

The basic issue addressed at this stage was an exploration of the reliability of all questionnaires when used with a large sample. Another important issue was to test the factor structure and compare it with the literature. All the scales showed a high level of reliability and for the subscales all the measures revealed a high or acceptable level of reliability when used with large samples of mothers of TD and ID children.

With only few differences reported between these two samples, the two groups showed an almost similar factor structure for all scales. Whereas, when factor analyses between Saudi and western literature were compared, sometimes differences were apparent, sometimes similarities. For the HADS and SDQ, similarities between the two cultures' results were reported with no differences at all in these two scales. Whereas, with negative items in the first factor and positive items in the second, SPS, which tests the satisfaction with social support, revealed nothing in common with the literature (Cutrona & Russel, 1987), which might be due to differences between cultures in what might be regarded as satisfactory support.

According to the Brief COPE, PSI-SF, and FSS, similarities between this study and the literature were greater than the differences. For the Brief COPE, as mentioned before, two belief items were added to the Arabic version. The results presented three types of coping strategies: emotion-focused, problem-focused and religious. These results were comparable to those of Lazarus and Folkman (1984) that presented two types of coping strategies, problem-focused and emotion-focused coping. However, as reported in the first study, because of the importance of religion to all Saudi mothers, the new coping strategy, religious coping was added to Lazarus and Folkman's making three coping strategies in all, which is similar to what was reported by Hastings et al. (in press).

As in the original study (Abidin, 1995), three factors of the PSI-SF were shown: DC, P-CDI, and PD. Only items 2 "I find myself giving up more of my life to meet my children's needs than I ever expected", 22 "I feel I am: 1. not very good at being a parent, to 5. a very good parent", and 24 "sometimes my child does things that bother me just to be mean" did not factor as they did in the literature. In this study, items 2 and 22 are parental distress (PD) instead of  the difficult child (DC) and parent-child dysfunctional interaction (P-CDI) used in Abidin (1995) and item 24 is difficult child (DC) instead of parent-child dysfunctional interaction (P-CDI) in Abidin (1995).

The results also revealed significant differences between mothers of TD children and mothers with ID children in all maternal well-being states with a higher level of stress, anxiety, and depression shown by mothers of ID children. Although there were significant differences in anxiety ($p<.01$), means were considered convergent (ID=8.89 & TD=8.16).

Regarding social support, the ID group reported a significantly a lower level of helpfulness, a lower number of sources of support and a lower level of satisfaction with support than the TD group. Finally, with regard to coping strategies, the ID group showed a lower level of using coping strategies than mothers of TD children. They used problem-focused coping, emotion-focused coping and religious-focused coping less than the TD group. Problem-focused coping and emotion-focused coping showed high differences between the two groups, whereas religious coping showed similar means (ID=14.53, TD=14.92) between the two groups even though differences were significant.

Differences between Saudi and western (north-American/UK) mothers of children with and without ID showed significant results in all maternal outcomes, with higher levels of stress, and anxiety, however, depression was also reported to be significant between the ID groups. Differences between Saudi mothers of TD children and mothers of children with ID showed more stress, anxiety and depression reported by mothers of children with ID.

**Study 4 (Answering the core questions):**

At this stage, after controlling for family, child's and mother's characteristics, three core questions were examined in order to test the study model:

1. Does child's IQ or BD predict maternal well-being (stress, anxiety and depression) after controlling for other factors?

Before answering this question, child, mother and family characteristics were entered in a correlation matrix in order to select only the significant correlate variables with maternal stress, anxiety or depression. The results revealed that child age showed a significant correlation to all maternal outcomes (stress, anxiety and depression). Child gender correlated significantly with maternal stress and depression. Whereas child's other disability, disability in another family member and family income correlated significantly with stress and anxiety. Finally, polygamy showed a significant correlation only with maternal stress. These variables were entered in the next step in order to test which type of child disability, IQ or BD, predict maternal well-being (stress, anxiety and depression) after controlling for other factors.

After controlling for the child and family characteristics, IQ showed a significant effect only on maternal stress and anxiety, but not on depression. Whereas BD showed a highly significant effect ($p<.001$) on all maternal well-being phases (stress, anxiety and depression). Hence, child BD was the intellectual disability representative used as the dependent variable in the study model. Moreover, BD and IQ were entered in an additional regression analysis as predictors of maternal stress and anxiety in as exploratory analyses.

2. Are the links between child disability and maternal well-being (stress, anxiety, and depression) mediated by coping and social support?

Multiple regressions revealed that problem-focused coping has a direct effect on maternal well-being (stress, anxiety and depression). Emotion-focused coping showed a significant effect only on maternal stress. This means that the use of emotion-focused coping is related to a higher level of maternal stress, whereas the use of problem-focused coping is related to a lower level of maternal stress, anxiety, and depression. Religious coping showed a direst effect only on maternal anxiety. There is no evidence that coping acts as a mediator of the relationship between BD and maternal well-being (stress, anxiety and depression).

Regarding social support, satisfaction with social support (SPS) and helpfulness of support (FSS) showed a significant direct effect on maternal stress and depression. Furthermore, support network size (FSS2) showed a direct effect on maternal depression. That means the low satisfied the mothers and more sources of support available to her are related to higher depression symptoms, which might be related that living within an extended family with unsupportive members, may lead to more depression. There is no evidence that social support acts as a mediator in the reaction between BD and maternal well-being (stress, anxiety and depression).

3. Are the links between child disability and maternal well-being moderated by coping, social support and family structure?

Results showed that only religious coping showed any significant moderating effect between child BD and maternal stress and anxiety. Emotion-focused coping showed nearly significant moderating effect between child BD and maternal anxiety. Mothers who used a low level of emotion-focused coping showed less maternal anxiety, whereas those who used a high level of emotion-focused coping showed a higher level of anxiety. Problem-focused coping did not show any significant moderating effect on maternal well-being (stress, anxiety and depression).

Regarding social support, no moderating effects were reported of any social support categories on maternal well-being. However, the satisfaction with social support (SPS) was reported a near to significant level as a moderator between child BD and maternal anxiety.

Regarding family structure, multiple regressions did not show any significant moderating effect of family structure on all maternal anxiety and depression. However, there was a significant direct effect of family structure only on maternal stress, with a higher level of stress reported by mothers living in a nuclear family than those in an extended family.

## 11.2. Summary and discussion of the remainder of the research findings:

Although there is a growing body of research that highlights the experiences of families with ID children, still very few, or maybe none, on the well-being of mothers of ID children have been conducted in Saudi Arabia.

The initial results of this study (Study 1) focused on mothers' own views of their situations. They reported their situation as being more stressful, anxious, and depressed than others, which concurs with previous studies that parents of children with disabilities appear to experience higher levels of stress, anxiety and depression than other parents (Blacher et al., 1999; Glidden & Floyd, 1997; Hadadian, 1994, Hanson & Hanson, 1990; Roach et al., 1999; Seltzer et al., 2001; Singer et al., 1999; Thome & Alder, 1999; You & Tsang, 1984). Emotion-focused coping was reported to be used more by mothers of ID children than problem-focused coping, which might be one of the reasons for these mothers feeling more stressed, anxious and depressed and which accords with Billing and Moos (1981), Billing and Moos (1994) Essex, Seltzer and Kraus (1999), Kramer (1997) and Lutzky and Knight (1994), who reported that emotion-focused coping is associated with higher levels of stress. Religious coping was viewed by all mothers as the most important strategy in helping them to overcome their emotional problems. Likewise, religion has been reported in the literature as one of the most important predictors of family stress and well-being (Cooper, 2003; Frey, Greenberg & Fewell, 1989; Friedrich et al., 1988; Weisner, Beizer & Syloze, 1991 & Werner & Smith, 1992).

Informal types of social support, especially from the family, were used more than any other type of support (Dunst, Trivette & Cross, 1986; Abercrombie, Hill & Turner, 2000). These mothers of children with ID preferred to live in an extended family, especially of a modified type, which they thought provided good support to them and their children. However, this result cannot be generalised, because in the case of mothers of TD children where there is no need for grandparents' support in the day-to-day tasks of looking after the children, mothers might prefer to live in a nuclear family.

Regarding the translation technique (Study 2), Vallerand's methodology in cross-cultural translation has proved to be a good way to find valid and reliable translated measures, although sometimes it might need one more step, as this study did, to provide the researcher with a good start. This is the interviewing step, which I believe is important before starting any further analysis. Interviews can show whether the measure is adequate for use in other cultures or with a specific group of participants. Modifying, adding, or deleting some items as a result of the experience with interviews and even sometimes a decision to change the whole measure and choose another can be another alternative as a result of the interviews.

In the light of the interview results, in addition to some minor changes in some items of the PSI-SF (item 8), and FSS (items 2, 4, 5 and 7), two items were added to the Brief COPE (items 29 and 30), "going to the cinema" has deleted from item 19 and two items "using alcohol or drugs" were completely modified (items 4 and 11). Although item 9, the "butterflies" expression, in the HADS does not have any equivalent in Arabic, this statement was literally translated and it had the lowest reliability when used with Arabic participants (El-Rufaie, 1987). In this study, item 9 (I get a sort of frightened feeling like "butterflies in the stomach") was clarified and slightly modified. These new items showed a significant level of reliability, which enabled them to be used as part of the new modified scales.

The factor structure of all scales (Study 3), except of the SPS, was approximately or exactly the same as has been reported in the literature. (Abidin, 1985; Carver, 1987, Cutrona & Russel, 1987; Dunst, Trivette & Hamby, 1994;Goodman, 1995 & Zigmong & Snaith, 1983). The PSI-SF revealed three factors, parental distress (PD), parent -child dysfunctional interaction (P-CDI), and difficult child (DC). All the items have been factored in a similar way as in the literature, except for item 2 "I find myself giving up more of my life to meet my children's needs than I ever expected", item 22 "I feel that I am: 1. not very good at being a parent, to-5. a very good parent" and item 24 "sometimes my child does things that bother me just to be mean".

Item 2 was "parental distress" (PD) which became the difficult child (DC) item in this study. In addition, items 22 and 24 were parent-child dysfunctional interaction (P-CDI) in the original study (Abidin, 1995), which became in this study parental distress (PD) and 24 difficult child (DC). These slight changes might be regarded as cultural differences in the interpretation of difficulties with children. However, I believe that item 22 might factor differently because it was written in the questionnaire in a different way from the other items. All the items should be answered from "strongly agree to strongly disagree", whereas items 22 and 32 should be answered from "1 to 5" (see Appendix 4), which might sometimes have confused mothers. These two items were the most inquired about when mothers were answering the questionnaires. In addition, these two items, and sometimes item 33, were the most commented upon when the questionnaires were returned. Hence, it is important when this questionnaire is used in further studies, to standardise all questions either to 1 to 5 or to strongly agree to strongly disagree.

Regarding the Brief COPE, in the literature there were two coping strategies, problem-focused and emotion-focused (Lazarus & Folkman, 1984). Whereas, because of the importance of religion in a Saudi mother's life, religious coping was considered as an independent factor, along with the other two coping strategies, emotion-focused coping, problem-focused coping, Hastings et al. (in press) showed an independent religious and denial coping, which supported this study's results, that religion sometimes, and especially during times of crisis, is considered to be an independent source of coping.

Because of the privacy of Saudi society, FSS showed different factors from the literature (Dunst, Trivette & Hamby, 1994). Husband, parents, parents-in-law, own family and husband's family were combined to factor as "family support". Professional agencies, professional helpers, the child's and family doctor, school-day-care, health centre, early intervention programme and place of worship were combined to form an "instrumental formal support". Co-worker support, parent group, social group/club, and other parents form a third factor "informal support". Finally, children and friends form a "offspring and friends support". This might be slightly different from the literature (Dunst, Trivette and Hamby, 1994), which reported five types of social support, partner/spouse, informal kinship, formal kinship, social organization and professional services. However, all these sources of support factored in according to cultural differences as we expected. Only the support of own children factored with friends, similarly to Dunst, Trivette and Hamby's (1994) which was expected to be under "family support". It might be useful if we tested differences in the amount of support given by children at different ages because it might be that support by older children is a more important family support of mothers than that of younger children.

The HADS, and the SDQ reported exactly similar results to those in the literature with 2 factors in the HADS, anxiety and depression (Zigmond & Snaith, 1983), and five factors in the SDQ, emotion symptom scale, conduct problems, hyperactivity, peer problems and prosocial scale (Goodman, 1997).

Whereas the SPS, which was used to test the degree of satisfaction with social support, did not show any similarities to the literature (Cutrona & Russel, 1987). In this study, all negative items gathered in one factor, while all positive items gathered in another. That means that, although the six sub-scales of SPS (guidance, reassurance of worth, social integration, attachment, nurturance, and reliable alliance) were correlated and showed a high level of internal consistency, they might be not representative of the five factors when used with Saudi mothers, who did not show any other variability of answering these measures rather than negative and positive factors. This might lead us to the importance of establishing a new "Arabic scale" of satisfaction with social support and to test its correlation with these results.

These results addressed the appropriateness of all of these measures when used with Saudi mothers. However, the satisfaction of social support needs to be re-examined with a new Arabic confirmatory questionnaire in order to establish whether or not mothers will factor the items in similar ways to those reported in this study. Until then, this scale should be used with caution.

Differences between Saudi and western mothers of typically developing (TD) children showed differences in levels of maternal well-being (stress, anxiety and depression) with a significantly higher stress and anxiety level shown by Saudi mothers, whereas western participants showed an insignificantly higher level of depression, which means no difference between the Saudi and western samples in depression level. Saudi mothers reported using to use more coping strategies (active coping, denial, emotional support, behavioural disengagement, venting, positive reframing, planning, humour and religion) than western mothers with no differences between the two groups in self-distraction, acceptance and instrument support. Regarding social support, western mothers rated helpfulness of social support higher than Saudis, however, satisfaction with social support was sometime higher in Saudi mothers and sometimes higher in western ones.

Regarding differences between Saudi and western mothers of Intellectually Disabled (ID) children, Saudi mothers of children with ID were more stressed, had more mental health problems, received less support and reported more child behavioural problems than western mothers. In addition, mothers in this study used more coping strategies than western samples. Regarding coping strategies, Saudi mothers used significantly more strategies than British mothers ($p<.001$) for all coping sub-scales (Pitten Cate, 2003). Only British mothers showed significantly more acceptance than Saudi mothers ($p<.05$).

There are very strong differences between Saudi and western mothers of children with and without disabilities. In general Saudi mothers were more stressed and anxious than western mothers, although they use more coping strategies, the helpfulness of the social support they received was lower which might be the cause of these differences. Some reasons were mentioned before regarding the differences between Saudi and western samples of TD children (Chapter 9), where it was said that the differences between Saudi and western samples in maternal stress and anxiety might be explained by the fact that the samples were not 100% comparable for all questionnaires used. Mothers were recruited in the Saudi study, whereas with the western samples undergraduate students, public school teachers, nurses, or both mothers and fathers were recruited.

However, in reality there might be more reasons for these results. The main and the most important reason for theses differences in the status of women in Saudi Arabia. They are more dependent on others in respect of most of their important life issues. Because of unemployment, for example which affects more than 74% of Saudi mothers and which arises from the limited opportunities for women to work in the field in Saudi Arabia. Even many of the highly educated mothers were unemployed (65% of the TD group and 84% of the ID group). This makes mothers more dependent financially on the male members of their families, their husbands, fathers, brothers or even their adult sons.

The total separation between males and females might place more burdens on mothers of males who do not know any thing about their sons' school environment. They cannot follow their sons' progress and always need someone as a mediator between them and the school. In addition, mothers of children with ID might suffer more than those in the west because of the shortage of services and especially of specialized rehabilitation health services, which are available in limited centres only in the main cities (Al-Hammadi, 2000). Furthermore, since there is very limited interest in intellectually disabled adults and the elderly in Saudi Arabia, mothers of children with ID, as they reported in the interviews, always think of their children's unknown future when they reach 14 when their registration at their school comes to an end.

The second main reason for differences between Saudi and western mothers is related to their children's behaviour. As I believe Saudi children might not have significantly higher behavioural problems than western children, but the cultural differences in the way behavioural problems are defined might differ between Saudi and western mothers, since some behaviours are very acceptable in western cultures, they are considered to be "behaviour problems" in Saudi culture. For example, some problems might not be an issue with western mothers, but they cause distress to Saudi mothers, such as when the child insists on eating with his/her left hand (as mentioned by some mothers in Study 1), which is not acceptable from the Islamic point of view and might be considered as a bad behaviour, and this can lead to others criticising the mother and thus to more stress to her. In addition, even at the early ages of 9 or 10-years-old, many families teach their children, especially daughters, not to talk or to make contact with any male, even in public places. Girls who break these rules, even if they smile at another boy, are considered to be behaving badly, which might put additional burdens on their mothers. Social relations between the child and others, especially the family, have very different criteria, which is completely different from the situation in the west.

Another important reason for the differences is that mothers in Saudi Arabia are responsible for their children until they are married, even if they are adults whereas western children typically become independent when they go to college. This might place more burdens on mothers who take care of a greater number of people than their western counterparts and who are always responsible for the failure of their children. This is a very quick look at the reasons for Saudi mothers reporting different results from those reported in western literature.

The relationship between ID and parental stress has been the subject of a large number of recent studies (Blacher & Hatton, 2001; Hatton & Emerson, 2003; Henker & Heller, 2000; Abidin, 1995; Deater-Deckard & Scarr, 1996) and, along with our results, these studies suggested that parents of children with BD experience greater levels of stress than parents in comparison groups.

Regarding social support, the results of this study showed a lower level of support and a lower level of satisfaction with social support in mothers of ID children than those of TD children. That might be because many families of the disabled group had migrated to Jeddah and Makkah from smaller cities and villages in order to find adequate education and health services, because schools and institutes for children with ID were not available in small cities and villages. In addition, health services specially for disabled children are still poor in most small cities and villages, which forces families to migrate either to Jeddah or to Makkah. That separates them from their families and might affect the support they receive compared to the TD group, who usually receive the support they need because they live near their families.

As reported in the literature on mental health problems (anxiety and depression), mothers of children with ID reported them more frequently than mothers of TD children (Glidden & Floyd, 1997; Harris, McHale, 1989; Mastroyannopoulou et al., 1999; Roach et al., 1999; Singer et al., 1999 & Thome & Alder, 1999). This study replicates these findings.

Mothers of ID children used coping strategies less than mothers of TD children. However, religious coping showed approximately the same results in both groups, which is to say that most of the mothers of ID children reported a lower use of all types of coping except religious. These mothers lost their trust in any of the ways of coping because there were no programmes to help them or to teach them how to cope or what effective coping strategy they should use. The few available intervention programmes in Saudi Arabia focus just on children and do not have any places for mothers and families. In addition, the religious education provided in schools and the media encourages mothers to focus on religious coping, because that it is the only way of coping they know and trust. Their trust in rewards from God makes them concentrate more on this type of coping. This drew our attention to the importance of intervention to mothers and families as well as children.

This study is considered unique in examining the effects of all types of family, the child's and the mother's characteristics and then controlling for the significant ones. Although level of education, type of school, other disabilities, mother's age, parent's kinship, marital status, maternal education, occupation and number of children, were hypothesised to have a direct effect on child disability, none of them showed any significant correlation with maternal well-being (stress, anxiety and depression). However, the child's age, gender, other disability, disability in another family member, polygamy, and family income were the only child and family characteristics that showed any significant correlation with maternal well-being (stress, anxiety or depression).

The child's age, gender, disability in another family member, polygamy, and family income showed significant effect on maternal stress. A higher level of stress was reported by mothers of younger children than those with older ones, agreeing with previous results that families with older children show better adjustment and less stress than those with younger children (Fitzgerland, Butler & Kinsella, 1990). Because of the importance of the male child in all Arab, and especially Saudi cultures, as reported in the literature, and as illustrated by the fact that Saudi parents usually carry the name of their first male child for the rest of their lives (father of, and mother of), the family and especially the mother suffers more from stress, as reported in this study in cases where something serious happens to their sons. As expected, the presence of more than one disabled person within the extended family places more stress on mothers than on those with only one disabled member in the family. In addition, mothers who live in polygamous families reported higher levels of stress than those in "one-wife" families.

The child's age, other disability, disability in another family member, and family income showed significant effects on maternal anxiety. Mothers of younger children who have more than one disability showed a lower level of anxiety than those of older ones, which coincided with the many studies which have reported that families of older children show better adjustment and less stress than those with younger children (Fitzgereland, Butler & Kinsella, 1990) and it was reported that younger children may be more stressful for parents than older children (Mash & Johnson, 1983). On the other hand, it was proved by many studies that the effect of multiple disabilities on the child and the family is higher than those who suffer from one disability (e.g. Mirza, 1993). As reported with regard to stress, the presence of more than one disabled person within the extended family causes a higher level of anxiety in mothers than in those with only one disabled member in the family. Furthermore, family income showed a negative effect on maternal stress, which coincided with the findings in the literature, that families with a low income showed a higher level of stress (Black, Molaison, & Smull, 1990; Dunst, Trivette & Cross, 1986; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984; Minnes, 1988).

Levels of depression were affected by the child's age, gender and disability in another family member. An intellectually disabled younger child puts a higher level of depression on his/her mother than an older child, agreeing with previous results that families with older children show better adjustment and less stress than those with younger children (Fitzgereland, Butler & Kinsella, 1990). Mothers suffer more from depression, as reported in this study, in case where something serious happens to their sons which might be because in Arab and especially Saudi cultures parents carry their fist baby's name for the rest of their lives, especially if he is male, and it brings delight to parents when they are called by their first child's name rather their own names, but which might put more burdens onto parents if their first child is disabled. Along with most findings in the literature, having more than one disabled family member cause more psychological problem to the mother.

A very important step in this study was to find which aspects of child disability might be stressful to mothers (IQ or BD). After controlling for all significant mother and child characteristics, BD was shown to be the significant predictor of maternal well-being (stress, anxiety and depression), while IQ was shown to have a significant effect only on stress and anxiety, but not on depression. Some studies reported that, according to the level of IQ (mild, moderate, severe and profound), the more severe the child's disability, the less adjustment and the more stress was reported by parents (Tasse' & Lacavalier, 2000). On the other hand, other studies focused on the effect of BD on parental outcomes. For example, Orr, Cameron and Day (1991) found that the more severe the child's BD, the greater the stress reported by parents.

IQ did not show any significant effect on maternal depression either, because all participants fell within the mild and moderate ID range and some of them with borderline. IQ might show a significant effect if severe and/or profound ID was also present. The other justification might be that the Stanford-Binet test was the only test which I did not examine; I depended on the children's IQ reported in their school files, and I also did not test-retest its reliability. There is a very small chance that because of the large numbers of children in each school, especially in state schools, and that usually there is only one person to examine all the children, this measure might not have been uniformly applied by everyone. According to Backer, Blachert, Crinc and Edelbroke (2002) that a child BD was a much stronger contributor to parenting stress than was the child's cognitive delays because very stressed parents misperceive and misreport their children as having more BD, thus creating the apparent relationship between these domains. They also believed that very stressed parents through their parenting, actually create more behavioural problems in their children.

Regarding coping strategies, the literature either reported a mediating effect (Benight & Harper, 2002; Lazarus & Folkman, 1984; Payne & Stoneman, 1997; Thompson et al., 1993) or a moderating effect (Wallander, 1989) of coping strategies, whereas in this study coping strategies, religious coping, were shown to have a moderating effect between child BD and maternal outcomes (stress and anxiety). Religious coping also showed a significant moderating effect between IQ and anxiety. Emotion-focused coping also showed a significant moderating effect between child BD and maternal anxiety, with a higher level of anxiety shown by mothers who focused on emotion-focused coping.

Social support was not reported as a mediator between child BD and maternal well-being. However, satisfaction with support (SPS), had a nearly moderating effect of child BD upon maternal anxiety. Whereas the support network size (FSS2) showed a significant moderating effect between IQ and maternal stress. The helpfulness of social support (FSS) showed nearly significant ($p=.06$) moderating results between IQ and maternal stress.

Finally, family structure did not show any effect on maternal well-being (stress, anxiety and depression) but, it showed a significant direct effect on maternal stress, increasing it, only in those living in a nuclear family.

The results of the moderating and mediating effect focused on the importance of religious coping in the Saudi culture. Religious coping was reported to moderate the relation between BD and stress, the relation of BD to anxiety, and the relation of IQ to anxiety. Sometimes the significant level was low, which might be because there were only four items in the Brief Cope which represented religious coping. If these items were expanded to an independent religious coping scale, which might focus more on different religious practices, the significance level of religious coping as a moderator might increase.

The emotion-focused coping showed a significant moderating effect on maternal anxiety, whereas problem-focused coping did not show any significant moderating and mediating results, which indicates that Saudi mothers, like other Arabic mothers, focused more on their emotional than their rational feelings. These results are as reported by the mothers in Study 1 (Chapter 7): that they depend on religion and their faith in God in order to overcome their problems. Furthermore, most of the results reported in Study 1 reported that these mothers did not use problem-focused coping and most of them relied on the emotional coping.

Regarding to social support, the SPS and FSS showed a nearly significant moderating effect between child BD and maternal anxiety (SPS) and between child IQ and maternal stress (FSS), whereas the FSS2 showed a significantly moderating effect between child IQ and maternal stress.

## 11.3. Limitations of the present research:

Some methodological limitations of these studies need to be discussed. The first potential limitation of this thesis is that all the measures used are of a self-report or maternal-report scales. It would be worth collecting teachers' data on children's BD, because sometimes mothers of TD children may have an idealized view of their children and sometimes mothers of children with ID have overestimated their children's BD as compared with other children.

Regarding timing, I believe that the mothers' answers might have been affected by the questionnaires being distributed only a few days before the war on Iraq, the unstable situation of those days putting extra anxiety and depression on most people living in Saudi Arabia, including the mothers in this research. This did not apply to mothers of TD children who were recruited several months before the mothers of children with ID.

Another prospective limitation is that the SDQ was only used with mothers with ID children and it may have been interesting also to collect data on their TD peers. This is because this questionnaire was not included in the first two studies which focused on the reliability and validity of the Arabic questionnaires and then compared the two groups of mothers with and without ID. In the early stages of this thesis, IQ was the only predictor, which hypothesised to represent child ID. This hypothesis has been modified in the later stages and BD was entered into the study model as a representative of child ID. Because of that, SDQ was not included in the study when a comparison between mothers of children with and without ID was conducted. We tried to overcome this limitation by presenting a comparison of this study with previously published studies. There remains a need for future studies to collect data of Saudi mothers of TD children.

Regarding the first study, interviews were conducted with mothers of ID children. Hence, the results gave the mothers' points of view about stress, family structure, mental health, and coping strategies which cannot be generalized to mothers of TD children or to fathers. For example, results of the interviews showed that there were significant numbers of mothers of ID children who prefer to live within their extended family because of their children's condition, these mothers reported a pressing need to live with or near to someone. Theses results could not be generalized to all Saudi mothers, as mothers of TD children might report a different opinion about living with their extended family, since they do not have the special needs which were reported by the mothers of ID children.

When comparing the characteristics of the child and mother, IQ did not have any direct effect on maternal well-being. IQ was the only variable which has not been tested by the researcher; results of the Stanford-Binet test were collected from the children's files. These tests had been conducted by either the school social workers, psychologists or doctors. It may have been interesting to test-retest the reliability and the validity of the IQ, as was done with all the other measures used in the study. As mentioned before, there is a very small chance that because of the large numbers of children in each school and especially in state schools, this measure might not have been applied uniformly by everyone.

## 11.4. Concluding remarks:

This thesis is unique in several ways. First, to the best of the researcher's knowledge, this study is the first of its type in the area of mothers' maternal stress, coping, social support, and mental health in Saudi Arabia. Thus, it will help to develop an understanding of the problems faced by the mothers of children with ID in that country. For example most of the mothers of children with ID depend more on informal support and especially family support. Many of them do not know about the services or the benefits available to disabled people. As a result, by focusing on the importance of formal support along with informal support mothers should seek formal support more than they do now.

Second, the study provides information that could help families who have children with ID. Ultimately, based on that information, programmes and strategies could be designed to help improve the quality of health and educational services provided for those people.

Third, children with disabilities will certainly benefit from such improvement. This is especially significant since parents of children with ID are known to suffer more from stress, anxiety and depression; thus, their children may suffer more than others from their parents' mental health status and when the parents mental health becomes better, this will improve the mental health of all family members such as siblings and grandparents, in the case of the extended family.

Fourth, the study will help to direct people's attention in the country not only to children with ID, but also to their families, since there is no governmental or non-governmental organization which takes care for these families. Furthermore, in the whole Kingdom there is no club or place for families to meet and to share their experience, and no counselling programmes for families in any of the institutes or the schools. People in Saudi Arabia are uninformed about the difficulties these families face because of the shortage of publication about families. Thus, this study will help to create a critical level of awareness, which may in turn stimulate more research in the field of special education as well as in related fields.

Fifth, since most of the research in this area has been conducted in the U.K and the U.S.A, it is good to bring in different experiences from different place and cultures, which help to improve the overall knowledge about the families of children with ID.

## 11.5. Suggestions for future studies:

Recommendations for future studies, based on the findings of this study, become apparent. The use of multiple information could strengthen the validity of the findings. Different information from teachers, fathers or health professionals would be valid.

For logistic reasons the sample of the present study was taken from an urban Saudi community. First future research would benefit from these results to expand the sample to rural areas or may be to compare these results with different areas in the Kingdom.

Since the literature showed strong stigmas on ID children and their families, future studies could also attempt to include stigma in the model in order to find its mediating or moderating effect on maternal well-being.

Since religion is conceived of as an integral part of Saudi culture and has been shown in this research to be the most important coping strategy used by mothers (Study 1) and as a separate coping factor (Study 3), accurate measurement of its influences on Saudi families is vitality important. Particularly, there is a pressing need to develop a Saudi religious coping index which would measure different kinds of religious coping due to the variety and sometimes conflict, of Islamic beliefs and practices (eg. Sunna, Sheiah, Suffi, etc.).

Some behaviours reported by Saudi mothers to be problematic, such as when the disabled girl refuses to wear the veil, talking to strangers of the opposite sex (especially for girls), and eating habits such as eating with the left hand, which is hated by Islam, these kinds of problem will never cause any stress to western mothers, which indicates that there is a need to establish a new Arabic scale for testing BD and then to test the same model to see wheather there will be any significant differences in results.

Finally, it might be useful to compare the results of this study with a new study of Saudi fathers of children with and without ID.

## 11.6. Practical implication of the research:

At the end of this work and as a result of the study some recommendations are suggested to practitioners and services in Saudi Arabia. Firstly, regarding practitioners, there is a need for qualified staff to work with children with ID since there is only one department of special education in King Saud University to serve schools and institutes in the whole kingdom. It was obvious during the collection of the data for this research that some of the staff who work with disabled children, especially in state schools, had graduated in another field and were not adequately qualified to work with those children. The staff who work with children with ID need continuous training and qualification by attending workshops and short courses to update their information.

Secondly, a great deal still needs to be done with regard to services for people with ID. For example, voluntary services are not known at all in Saudi Arabia. It is very vital to highlight the importance of voluntary works which is very effective in improving services and the importance of non-governmental organizations (NGOs) in running this kind of service. Furthermore, there is a lack of disability research centres and a dearth of publication in the field of ID to stress the need for more research centres because NGOs and services in general need to be expanded in all disability fields.

Finally, both governmental or non-governmental education and rehabilitation services focus only on children up to 14-years-old, there is no continuity of most of the services is not obtainable for older children. This causes major mental health problems (anxiety and depression) for mothers. Hence, there is a need for more rehabilitation centres for ID adults and a need for continuing vital services of all kinds.

# REFERENCES

Abbott, D., & Meredith, W. (1986). Strengths of parents with retarded children. Family relations, 35, 371-375.

Abdel Rahman, A. I., & Morgan, S. P. (1987). Socio-economic and Institutional correlates of family formation: Khartum, Sudan. Journal of Marriage and the Family, 49, 401-412.

Abdrabbah, B. (1984). Saudi Arabia Forces of Modernization. U.S.A: Amana Book.

Abercrombie, N., Hill, S, & Turner, B. (2000). The Penguin dictionary of sociology. London: Penguin books Ltd.

Abidin, R. (1992). The determinants of parenting behaviour. Journal of clinical child psychology, 21(4), 407-412.

Abidin, R. (1995). Parenting Stress Index: professional Manual. Odessa: Psychological Assessment Resources, Icc. (PAR).

Abidin, R., Jenkins, C., & McGuaghey, M. (1992). The relationship of early family variables to children's subsequent bahavioural adjustment. Journal of clinical child psychology, 21(1), 60-69.

Abolfotouh, M. (1997). Behavioural disorders among urban schoolboys in Sout-western Saudi Arabia. Annals of Saudi Medicine, 3(2), 274-283.

Abu-Ali, M. (1988). Social behaviour aspects of children with mental retardation. Umm Al-Qura university, Makkah.

Affleck, G., Tennen, H., & Gershman, K. (1985). Cognitive adaptation to high-risk infants: The research for mastery, meaning, and protection from future harm. American Journal of Mental Deficiency, 89, 653-656.

Affleck, G., Tennen, H., & Rowe, J. (1990). Mothers, fathers and the crisis of newborn intensive care. Infant Mental Health Journal, 11, 12-25.

Ahmad, S. (1985). Rural-urban differentials in maternal fertility in four Moslem populations. Journal of Biosocial Science, 17(2), 157-165.

Aiken, L. S., & West, S. G. (1991). Multiple regression: Testing and interpreting interactions. Newbury Park: CA: Sage.

Akhdar, F. (1994). Childhood disability: Parents' perceptions and experiences in Saudi Arabia. Unpublished Ph.D, London University, London.

Al Husain, M., Salih, M., Zaki, O., Al Othman, L., & Al Nasser, M. (2000). A clinical study of mentally retarded children with fragile X syndrome in Saudi Arabia. Annals of Saudi Medicine, 20(1), 16-19.

Al-Ansari, S. B., H. (1997). Translation and adaptation of the revised Denver pre-screening developmental questionnaire for Medinah children, Saudi Arabia. Annals of Saudi Medicine.

Al-Awad, A. (1997). Childhood behaviour problems in urban Sudan. Southampton University, Southampton.

Al-Awad, A., & Sonuga Barke, E. (2002). The application of the Conners Rating scales to a Sudanese sample: An analysis of parents' and teachers' ratings of childhood behaviour problems. Psychology and Psychotherapy: Theory, Research and Practice, 00.

Al-Awad, A., & Sonuga Barke, E. (1992). Childhood problems in a Sudanese city: A comparison of Extended and Nuclear families. Child Development, 63, 906-914.

Al-Dosari, M. (1983). Jeddah. Journal of Al-Faisal Architecture Planning, 1(2), 13-16.

Aldwin, C. M. (2000). Stress, coping and development: An integrated perspective. New York: The Guilford Press.

Al-Essa, M., Al-Mehaidib, A., & Al-Gain, S. (1997). Parental awareness of liver disease among children in Saudi Arabia. Annals of Saudi Medicine.

Al-Essa, M., Rashed, M., & Ozand, P. (1998). Tyrosinemial type II. Annals of Saudi Medicine.

Al-Essa, Y. (1999). Child abuse and neglect in Saudi Arabia: What are we doing and where do we stand? Annals of Saudi Medicine, 18(2), 105-106.

Al-Essa, Y., Al-Sanie, A., Al-Alola, S., Al-Shaalan, M., Ghazal, S., Al-Harbi, A., & Al-Wakeel, A. (2000). Parental perceptions of fever in children. Annals of Saudi Medicine, 20, 202-205.

Al-Garni, M. (2000). The impact of family structure and family function factors on the Deviant Behaviours of high school students in Makkah city, Saudi Arabia. The Ohaio State University, Ohaio.

Al-Ghamdi, M. (1991). Socio-economic change, family and fertility in Saudi Arabia. University of Wales, Cardiff, Cardiff.

Al-Ghamdi, S. F. (1985). Folkore in the village and town at Al-Baha Area and city of Jeddah. Jeddah, saudi Arabia: Dar Al-Ilm Press.

Al-Hamdan, F. (1987). Ecological study of demographic changes in the city of Jeddah. Jeddah, Saudi Arabia: Dar Al-Mojtama Publication House.

Al-Hammadi, A. (2000). Future Challenges: A study of the needs of adults with disabilities and related policies in Saudi Arabia. University of Denver, Denver.

Al-Juwayer, I. (1984). Developmant and family in Saudi Arabia: An exploratory study of the views of University students in Riyadh. Unpublished Ph.D, University of Florida, Miami.

Al-Khashrami, S. (1995). Integration of children with special needs in Saudi Arabia. Unpublished Ph.D, University of Nottingham, Nottingham.

Al-Khateeb. , J. (1988). Behavioural Disorders in children with Intellectual Disabilitities (in Arabic). Studies, 8(15), 136-169.

Al-Kheraigi, F. (1989). Special education development in the Kingdome of Saudi Arabia from 1958 to 1987. Portland State University, Portland.

Al-Maghlooth, F. A. (1999). Caring and rehabilitation of disabled people in Saudi Arabia. Riyadh, Saudi Arabia: Taqnia Press.

Al-Marsouqi, H. (1980). A facet theory of attitudes towards handicapped individuals in Saudi Arabia. Mitchigan State University, Michigan.

Al-Muslat, Z. (1987). Educators' attitudes toward the handicapped in Saudi Arabia. Indiana State University, Bloomington.

Al-Obeidy, I. (1985). The incidence of infant mortality in a sample of households in Riyadh, saudi Arabia. Michigan State University, Michigan.

Al-Rajeh, S., Bademosi, O., Awada, A., Ismail, H., Al-Feraih, H., Dawodu, A., Chebib, F., & Assuhaimi, S. (1995). Community survey of nurological Disorders in Saudi Arabia. Annals of Saudi Medicine, 15(1), 32-35.

Al-Said, A. (1988). Saudi's attitudes toward fertility and family size. Michigan State University, Michigan.

Alsaif, A. F. (1991). Social work in Saudi Arabia: The development of a profession. Unpublished PhD, Florida State University, Tallahassee.

Al-Sammadi, A., & Al-Husain, A. (1996). Psychological problems that caused by the Arabic family system. Journal of Councelling, 5(89-114).

Alshaia, A. (1997). The presious pearl in the disabled: Religious questions and answers (in Arabic). Riyadh, Saudi Arabia: Dar Alsoma'ei.

Al-Suwaigh, S. (1989). Women in transition: The case of Saudi Arabia. Journal of Comparative Family Studies, 20, 67-78.

Alturaiki, M. (1997). The national research project on disability and rehabilitation and community-based rehabilitation in Saudi Arabia. Riyadh, Saudi Arabia: The joint centre for research in prosthetic and orthotic and rehabilitation program.

Alturaiki, M. H. (1998). Critical stages. Riyadh, Saudi Arabia: The Joint Centre for Research in Prosthetics and Orthotics and Rehabilitation Program.

Amaral, R. C. (2003). How do children with developmental disabilitries impact their parents' parental satisfaction, self-esteem, symptoms of stress, ways of coping, marital satisfaction and family support? Unpublished PhD, State University of New York, Buffalo.

Angenent, H., & De Man, A. (1996). Background factors of Juvenile Delinquency. New York: Peter Lang Press.

Aylard, P., Gooding, J., McKenna, P. & Snaith, R. (1987). A Validation Study of three Anxiety and depression self-assessment Scale. Journal of psychosomatic Research, 31(2), 261-268.

Ayyash-Abdo, H. (2001). Individualism and collectivism: The case of Lebanon. Social Behaviour and Personality, 29(5), 503-518.

Backer, D. T., H. (1997). The relationship between condition-specific morbidity, social support and material depriviation in pregnancy and early motherhood. Social Science and Medicine, 45, 1325-1336.

Bagader, A. A. (1984). The structure of Arab family: A field study of the City of Jeddah. Journal of the faculty of Arts and Humanities, King Abdulaziz, University press, 4, 253-274.

Baker, B., Blacher, J., Crinc, K., & Edelbrock, C. (2002). Behaviour problems and parenting stress in families of three-year-old children with and without developmental delays. American Journal on Mental Retardation, 6, 433-444.

Baker, B., Blacher, J., Kopp, C., & Kraemer, B. (1997). Parenting children with mental retardation: Academic press.

Baker, B., Landen, S. & Kashima, K. (1991). Effects of parent training on families of children with mental retardation: Increased burden or generalized benefit? American Journal on Mental Retardation, 96(2), 127-136.

Bakhsh, A. (1987). Characteristics of a medical and educational center for Down's syndrome children in Jeddah, Saudi Arabia. University of San Fransisco, San Fransisco.

Ballard, K., Bray, A., Shelton, E. J., & Clarkson, J. (1997). Children with disabilities and education system: The experiences of fifteen fathers. International journal of Disability, Development, and Education, 44(3), 229-241.

Baloush, N. (1990). Social support and maternal reaction in Saudi Arabian women with premature birth from a Neuman framework. D'Youville College, Buffalo, New York.

Banville, D., Desrosiers, P. & Genet-Volet, Y. (2000). Translating questionnaires and inventories using a cross-cultural translation technique. Journal of teaching in physical education, 19, 374-387.

Barber, P., Turnbull, A., Behr, S., & Kerns, G. (Ed.). (1988). A family systems perspective on early children special education. Baltimore: P.H. Brookes Publishing Co.

Barnett, W., & Boyce, G. (1995). Effects of Children with Down syndrome on parents' activities. American Journal on Mental Retardation, 100, 115-127.

Barr, J. H. (1983). Education for the handicapped in the Arabian Peninsula: Issues and Trends. Unpublished PhD, Teachers College of Education, University of Colombia, Colombia.

Barr, R. C. (1999). Reflections of measuring pain in infants: Dissociation in responsive systems and "honest signals". Neonatal Intensive Care, 12(3), 19-24.

Barron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical consedirations. Journal of Personality and Social psychology, 51, 1173-1182.

Beck, A. (2002). Maternal express emotion towards children with and without learning disabilities. University of Southampton, Southampton.

Beckman Bell, P. (1981). Child-related stress in families of handicapped children. Topics in early childhood special education, 1, 45-54.

Beckman, P. (1983). The influence of selected child characteristics on stress in families of handicapped infants. American Journal on Mental Deficiency, 88, 150-156.

Beckman, P. (1991). Comparison of mothers' and fathers perceptions of the effect of young children with and without disabilities. American Journal on Mental Retardation, 95, 585-595.

Beebe, S., Casey, R., & Pinto-Martin, J. (1993). Association of reported infant crying and maternal parenting stress. Clinical Paediatrics, Jan., 15-19.

Beresford, B. (1994). Positively parents: Caring for a severely disabled child (HMSO, Trans.). London.

Beresford, B. (1995). Expert Opinions: a national survey of parents caring for a severely disabled child. Bristol: The policy Press.

Beresford, B. (1995). Resources and strategies: How parents cope with the care of a disabled child. Journal of child psychology and psychiatry, 35(1), 171-209.

Beresford, B. (1996). Coping with the care of a severely disabled child. Health and social care in the community, 4(1), 30-40.

Berg, K. E., & Latin, R. W. (1994). Essentials of modern research methods in health, physical education, and recreation. Englewood Cliffs: NJ: Prentice Hall.

Berra, M. (Ed.). (1981). Social support in the adjustment of pregnant adolescents. Beverly Hills, CA: Sage.

Bigras, M. (1996). Discriminant validity of the parent and child scales of the parenting stress index. Early education and development, 7(2), 167-178.

Bigras, M., LaFreniere, P. & Dumas, J. (1996). Discriminant validity of the parent and child scales of the parenting stress index. Early education and development, 7(2), 167-178.

Billings, A., & Moos, R. (1981). The role of coping responses and social resources in attenuating the stress of life events. Journal of Behavioural Medicine, 4, 139-157.

Billings, A., & Moos, R. (1983). Comparisons of children of depressed and non-depressed parents: A social-environmental perspective. Journal of Abnormal Child Psychology, 11, 463-486.

Billings, A., & Moos, R. (1984). Coping, stress, and social respourecs among adults with unipolar depression. Journal of Personality and Social psychology, 46, 877-891.

Bin Batal, Z. (1998). An assessment of burnout and its correlates among special education teachers of hearing impaired, mentally retarded, and visually impaired students in special schools in the Kingdome of Saudi Arabia. The Pennselvania State University, Pennsylvania.

Bird, H. R. (1996). Epidemiology of childhood disorders in a cross-cultural context. Journal of child psychology and psychiatry, 37(1), 35-49.

Bird, J. B. (1995). Revolution for children in Saudi Arabia. In E. W. E. In Fernea (Ed.), Children in the Muslim Middle East (pp. 276-294). Austin, TX: University of Texas Press.

Birkel, R., & Repucci, N. (1983). Social networks, Information seeking and the utilisation of services. American Journal of Cmmunity psychology, 11, 185-205.

Blacher, J. (Ed.). (1984). A dynamic perspective on the impact of a severely handicapped child on the family. New York: Academic Press.

Blacher, J., & Hatton, C. (2001). Current prespectives on family research in mental retardation. Current Opinion in Psychiatry, 14, 477-482.

Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation: Implications for caregiving. Family relations, 46, 325-334.

Blacher, J., Nihira, K., & Meyers, C. (1987). Characteritics of home emviroments of families of mentally retarded children. American Journal of Mental Deficiency, 91, 226-236.

Blacher, J., Shapiro, J., Lopez, S., Diaz, L. & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. American Journal on Mental Retardation, 101(5), 483-496.

Black, M., Molaison, V. & Smull, M. (1990). Families caring foe a young adult with mental retardation: Service needs and urgency of community living request. American Journal on Mental Retardation, 95(1), 32-39.

Bond, M. S., P. (1996). Cross-cultural social and organizational psychology. Annual revision of psychology, 47, 205-227.

Boyce, G., Behl, D., Mortensen, L., & Akers, J. (1991). Child characteristics, family demographics and family processes: Their effects on the stress experienced by families of children with disabilities. Counseling psychology quarterly, 4, 273-288.

Breen, M., & Barkley, R. (1988). Child psychopathology and parenting stress in girls and boys having attention deficit disorder with hyperactivity. Journal of paediatric Psychology, 13(2), 265-280.

Breslau, N., & Davis, G. (1986). Chronic stress and major depression. Archeives of general psychiatry, 43, 309-314.

Brislin, R. (Ed.). (1980). Translation and content analysis of oral and written materials (Vol. 2). Boston: Allyn & Bacon.

Brislin, R. (Ed.). (1986). The wording and translation of research instruments. Beverly Hills: CA, Sage.

Bristol, M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. Journal of Autism and Developmental Disorders, 17, 469-486.

Bristol, M., & Schopler, E. (Ed.). (1983). Stress and coping in families of autistic adolescents. New York: Plenum Press.

Bristol, M., & Schopler, E. (Ed.). (1984). A developmental perceptive on stress and coping in families of autistic children. New York: Academic Press.

Bristol, M., Gallagher, J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. Developmantal psychology, 24, 441-451.

Brodfield, R. H., & Fones, D. M. (1985). Special Report. Academic therapy, 21, 91-97.

Bromely, B., & Blacher, J. (1989). Factors delying out-of-home placement of children of severe handicapps. American Journal on Mental Retardation, 94, 284-291.

Butler, L., & Meichenbaum, D. (1981). The assessment of interpersonal problem-solving skills. In P. C. K. S. D. Hollon (Ed.), Assessment stratigies for cognitive-behavioural intervensions (pp. 197-225). San diego, California: CA: Academic Press.

Byrne, E., & Cunningham, C. (1985). The effects of mentally handicapped children on families-a conceptual review. Journal of child psychology and psychiatry, 26(6), 847-864.

Byrne, E., Cunningham, C., & Sloper, P. (1988). Families and their children with Down syndrome. London: Routledge.

Cadman, D., Rosenbaum, P., & Pettingill, D. (1987). Prevention of emotional, behavioural, and family problems in children with chronic medical illness. Journal of Preventive Psychiatry, 3, 147-165.

Cahill, B. M., & Glidden, L.M. (1996). Influence of child diagnosis on family and parental functioning: Down syndrome Versus other disabilities. American Journal on Mental Retardation, 101(2), 149-160.

Calderone, R., &Greenberg, M. (Ed.). (1993). Consideration in the adaptation of families with school-aged deaf children. Hilssdale: NJ: LEA.

Cameron, S. O., R. (1989). Stress in families of school-aged children with delayed mental development. Canadian Journal of Rehabilitation, 2(3), 137-144.

Carver, C. (1997). You want to measure coping but your protocol's too long: Consider the Brief Cope. International Journal of Behavioural Medicine, 4(1), 92-100.

Carver, C., Scheier, M., & Weintraub, J. (1989). Assessing Coping strategies: A theoritical based approach. Journal of Personality and Social psychology, 56(2), 267-283.

Chamie, J. (1981). Religion and fertility. New York: Cambridge University Press.

Chetwynd, J. (1985). Factors contributing to stress on mothers caring for an intellectually handicapped child. British Journal of Social Work, 15, 295-304.

Clark, L., & Watson, D. (1988). Mood and the mundane: Relations between daily life events and self-reported mood. Journal of Personality and Social psychology, 54, 296-308.

Click, J. (1986). Grandparent concerns: Learning to be special. Sibling Information Netweork Newsletter, 5, 3-4.

Cogner, R. D., McCarty, J. A., Lahey, B. B., & Kropp, J. P. (1984). Perception of child, child rearing values, and emotional distress as mediating links between environmental stressors and observed maternal behaviour. Child Development, 55, 2234-2247.

Cole, D. (1986). Out-of-home child placement and family adaptation: A theoritical framework. American Journal of Mental Deficiency, 91, 226-236.

Cole, J. (2000). The effects of a rural parent education program on parenting stress, preceived social support, parental locus of control, and parental efficacy. West Virginia University, Morgantown.

Cole, J., M. (2000). The effect of a rural parent education program on parenting stress, perceived social support, parental locus of control, and parental efficacy. Unpublished Master, West Virginia University, West Virginia.

Collinsworth, P., Strom, R., Strom, S. & Young, D. (1991). The grandparent strengths and needs inventory: Development and factorial validation. Educational and psychological measurement, 785-792.

Compton, P., Coward, J., & Wilson, K. (1985). Family size and religions denomination in Northern Ireland. Journal of Biological Science, 17(2), 137-145.

Connolly, E. (1997). Chronic stress in mothers of severely disabled children: A rorschach study. Unpublished PhD.

Cooper, A. E. (2003). An investigation of the relationships among sprituality, pryer and mediation, and aspects of stress and coping. The Wright Institute.

Costeff, H. K., Z. (1996). The developmental profile of disadvantaged 6 year old children. The British Journal of Developmental Disabilities, XLII(82).

Cotrell, D., Hill, P., Walk, D, Deanaly J., & lorethou, A. (1988). Factors influencing non-attendance at child psychiatry out-patient appointments. British Journal of psychiatry, 152, 201-204.

Covert, S. (Ed.). (1992). Supporting families. Baltimore: Paul H. Brookes.

Creasey, G. L., & Jarvis, P. A. (1994). Relationships between parenting stress and developmental functioning among 2-year-olds. Infant Behaviour and Development, 17, 423-429.

Crinc, K., Friedrich, W. & Greenberg, M. (1983a). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88, 125-138.

Crinc, K., Greenberg, M. Ragonzin,A., Robinson, N., & Basham, R. (1983b). Effects of stress and social support on mothers and premature and full-term infants. Child Development, 54, 209-217.

Crockenberg, S. (1988). Stress and role satisfaction experienced by employed and nonemployed mothers with young children. Lifestyle, 9(2), 97-110.

Crowther, J. (1999). Oxford advanced learner's dictionary. Oxford: Oxford University Press.

Cunningham, C. (1982). Down's syndrome: An introduction for parents. London: Souvenir Press.

Cutrona, C. (1984). Social Support and stress in the transition to parenthood. Journal of Abnormal Psychology, 93(4), 378-390.

Cutrona, C., & Russell, D. (1987). The provisions of social relationships and adaptation to stress. Advances in Personal Relationship, 1, 37-67.

Cutrona, C., & Troumtman, B. (1986). Social support, infant temperament, and parenting self-efficacy: A mediational model of postpartume depression. Child Development, 57, 1507-1518.

Darsh, S. M. (1980). An outline of Islamic family low. London: Ta-Ha.

Deater-Deckard, K., & Scarr, S. (1996). Parenting stress among dual-earner mothers and fathers: Are there gender differences? Journal of Family Psychology, 10(1), 45-59.

Deluca, K., & Salerno, S. (1984). Helping professionals connect with families with handicapped children. Springfield, IL: Thomas press.

Department), M. o. I. F. I. (1999). Kingdom of Saudi Arabia: The march of progress. Riyadh, Saudi Arabia.

Diner, E., & Emmons, R. (1984). The independence of positive and negative affect. Journal of Personality and Social psychology, 47, 1105-1117.

Disabled welfare and their participation in jobs that fit with their age and disabilities in both sectors, private and public in Saudi Arabia. (1993). Riyadh, Saudi Arabia: The Social and Developmental Consultant Research Center.

Donovan, A. (1988). Family stress and ways of coping with adolescents who have handicaps. American Journal on Mental Retardation, 92, 502-509.

Dumas, J., Wolf, L., Fisman, S., & Culligan, A. (1991). Parenting stress, child behaviour problems , and dysphoria in parents of children with autism, Down syndrome, behaviour disorders, and normal developement. Exceptionality, 2, 97-110.

Dunst, C., Jankis, V., & Trivette, C. (1984). Family support scale: Reliability and validity. Journal of Individual, Family, and Community Wellness, 1(45-52).

Dunst, C., Trivette, C. & Cross, A. (1986). Mediating influences of social support: Personal, family, and child outcomes. American Journal of Mental Deficiency, 90, 403-417.

Dunst, C., Trivvette, C., Cross, A. (1986). Mediating influences of social support: personal, family, and child outcomes. American Journal of Mental Deficiency, 90(4), 403-416.

Dunst, T., & Hamby (Ed.). (1993). Family Support Scale. Cambridge: Brookline Books.

Dyson, L. (1991). Families of young children with handicapped: Parental stress and family functioning. American Journal on Mental Retardation, 95(6), 623-629.

Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. American Journal on Mental Retardation, 102(3), 267-279.

Dyson, L., Edger, E., & Crinc, K. (1989). Psychological predictors of adjustment by siblings of developmentally disabled children. American Journal on Mental Retardation, 94, 292-270.

Dyson, L., & Fewell, R. (1986). Stress and adaptation in parents of young handicapped and nonhandicapped children: A comparative study. Journal of the Division for Early Childhood, 10, 25-35.

Dyson, L. L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. American Journal on Mental Retardation, 98(2), 207-218.

D'Zurilla, T., & Nezu, A. (1980). A study of the generation-of - alternatives process in social problem-solving. Cognitive Therapy and Research, 4, 67-72.

Eapen, V., Naqvi, A. & Al-Dhaheri, A. (2000). Cross-cultural validation of Harter's Self-perception profile in the United Arab Emirates. Annals of Saudi Medicine, 20(1), 8-11.

Edeh, O. H., L. (2002). Cross-cultural comparison of interpersonal problem-solving in students with mental retardation. American Journal on Mental Retardation, 107(1), 6-15.

Education, G. S. f. S. (1992). Ministry of Education efforts in the field of disability. Riyadh, Saudi Arabia.

El Hag El Awad, M., & Adedoyin, M. (1994). Trends of nurological disorders in Saudi Childeren. Annals of Saudi Medicine, 15(2).

Elashwal, A. (1987). Encyclopedia of special education. Cairo: The Anglo-Egyptian.

Ellahi, R., & Hatfield, C. (1992). Research into the needs of Asian families caring for someone with a mental handicap. Mental Handicap, 20, 134-136.

El-Rufaie, O. (1987). Validity study of the Hospital Anxiety and Depression scale among group of Saudi patients. British Journal of Psychiatry, 151, 687-688.

El-Rufaie, O., & Absood, G. (1983). Retesting the validity of the Arabic version of the Hospital Anxiety and Depression (HAD) scale in primary health care. Social Psychiatry, 30, 26-31.

Emerson, E. (2002). Self-reported strength and difficulties of children and adolescents with and without developmental disabilities. Lancaster: IHR, Lancaster University.

Emerson, E. (2003). Prevalence of Psychiatric disorders in children and adolescents with and without intellectual disabilities. Journal of Intellectual Disability Research, 47(1), 51-58.

Emerson, E., Robertson, J., & Wood, J. (2004). Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities and urban conurbation. journal of Applied Research in Intellectual Disabilities(17), 77-84.

Epstein, L. (1987). Social support and depression in mothers of pre-school children referred to a child guidance clinic. University of Southampton, Southampton.

Erel, O., & Burman, B. (1995). Interrelatedness of marital relations and parent-child relations: A meta analytic review. Psychological Bulletin, 118, 108-132.

Erickson, M., & Upshur, C. (1989). Caretaking burden and social support: A comparison of mothers of infant with and without disabilities. American Journal on Mental Retardation, 94, 250-258.

Esdaile, S. A., & Greenwood, K. M. (1995). Issues on parenting stress: A study involving mothers of toddlers. Journal of Family Studies, 1(2), 153-165.

Essex, E., Seltzer, M. & Krauss, M. (1999). Differences in coping effictiveness and well-being aging mothers and fathers of adult with mental retardation. American Journal on Mental Retardation, 104(6), 545-563.

The Europa World Year Book. (1997). (Vol. 2). London: Europa.

The Europa World Year Book. (1999). London: Europa.

Ezinwanyi, O., O. (1999). Stress and coping: A test of the ABCX model on families caring for a member with disabilities. Unpublished Ph.D, Calgary,, Alberta.

Fandy, M. (1999). Saudi Arabia and the politics of dissent. New York: St. Martin's Press.

Faux, R. (2000). A description of the uses of content analysis and interviews in educational/Psychological research. Social Research, 1.

Featherstone, H. (1980). A difference in the family: Life with a disabled child. New York: Basic Books press.

Fehrenback, A., & Peterson, L. (1989). Parental problem-solving skills, stress and dietary compliance in phenylketonuria. Journal of Consulting and Clinical Psychology, 57(2), 237-241.

Felimban, M., Hanif, M., & Al-Almaei, S. (1998). Psychosocial impact on mothers of Saudi diabetic children in Riyadh, Saudi Arabia. Annals of Saudi Medicine, 18(4).

Ferguson, P. M., & Asch, A. (1989). Lessons from life: Personal and parental perspictives on school, childhood, and disability. In D. Bilklen, Ferguson, & A. Ford (Ed.), Schooling and disability: NSSE yearbook. Chicago: National Society for the Study of Education.

Fewell, R. (Ed.). (1983). Working with sensorily impaired children. Rockville, MD: Aspen.

Fewell, R. (Ed.). (1986). Support from religious organizations and personal beliefs. Austin: TX: PRO-ED.

Fewell, R. R. (1984). Source of support for mothers of children with Down syndrome. Paper presented at the Research on Mental Retardation and Developmental disabilities, Gatlinburg, TN.

Field, T., Healy, B., Goldstein, S., & Gutherz, M. (1990). Behaviour-state matching synchrony in mother-infant interactions of nondepressed versus depressed dyads. Developmental psychology, 26, 7-14.

Fisman, S., Wolf, N., & Noh, S. (1989). Marital intimacy in parents of exeptional children. Canadian Journal of psychiatry, 34, 519-525.

Fitzgerald, M., Bulter, B., & Kinsella, A. (1990). The burden on a family having a child with special needs. Irish Journal of psychological medicine, 7, 109-113.

Floyd, F., & Zmich, D. (1991). Marriage and the parenting partnership: Perceptions and interactions of parents with mentally retarded and typically developing children. Child Development, 62, 1434-1448.

Floyd, F., Phillippe, K. (1993). Parental Interactions with children with and without mental retardation: Behaviour management, coerciveness, and positive exchange. American Journal on Mental Retardation, 97(6), 673-684.

Flynt, S., & Wood, T. (1989). Stress and Coping of mothers of children with moderate mental retardation. American Journal on Mental Retardation, 94, 268-283.

Folkman, S. (Ed.). (1991). Coping across the lifespan: Theoritical issues. Hillsade, NJ: Lawrence Erlbaum Associates, Publishers.

Folkman, S. (1997). Positive psychological states and coping with severe stress. Social Science and Medicine, 45, 1207-1221.

Folkman, S., & Lazarus, R. (1980). An analysis of coping in middle-aged community sample. Journal of Health and Social Behaviour, 21, 219-239.

Folkman, S., & Moskowitz, J. (2000). Positive affect and the other side of coping. American Psychologist, 55, 647-654.

Folkman, S., Lazarus, R., Gruen, R., & Delongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. Journal of Personality and Social psychology, 50, 571-679.

Folkman, S., Lazarus, R., Pimley, S., & Novacek, J. (1987). Age differences in stress and coping process. Psychology and Aging, 2(2), 171-184.

Folkman, S., & Lazarus, R. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. Journal of Personality and Social psychology, 48, 150-170.

Forehand, R., Furey, W., &McMahon, R. (1984). The role of mental distress in a parent training program to modify child noncompliance. Behavioural Psychotherapy, 12, 93-108.

Forgays, D. K., & Forgays, D. G. (1993). Personal and enviromental factors contributing to parenting stress among employed and nonemployed women. European Journal of Personality, 7, 107-118.

Foster-Gaitskell, D. P., C. (1989). Comparison of parent and teacher ratings of adaptive bahaviour of children with mental retardation. American Journal on Mental Retardation, 94(2), 177-181.

Fouzan, E. (1986). The involvement of parents of educable mentally retarded in their children's educational programs in Saud Arabia. University of San Diego, San Diego.

Frankel, K. H., R. (1996). Depressed mothers: They don't always look as bad as they feel. Journal of American Academy of child and adolsent psychiatry, 35(3), 289-298.

Frey, K., Fewell, R., & Vadasy, P. (1989). Parental adjustment and changes in child outcomes among families of young handicapped children. Topics in early childhood special education, 8, 38-57.

Frey, K., Greenberg, M. & Fewell, R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. American Journal on Mental Retardation, 94(3), 240-249.

Friedrich, W., Cohen, D., & Wilturner, L. (1988). Specific beliefs as moderator variables in maternal coping with mental retardation. Journal of Children's health care, 17, 40-44.

Friedrich, W., Greenberg, M., & Crinc, K. (1983). A short-form of the questionnaire on resources and stress. American Journal of Mental Deficiency, 88, 41-48.

Friedrich, W., Wilturner, L., & Cohen, D. (1985). Coping resources and parenting mentally retarded children. American Journal of Mental Deficiency, 90, 130-139.

Friedrich, W., & Friedrich, W. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. American Journal of Mental Deficiency, 85, 551-553.

Furey, E. M. (1994). Sexual abuse of adults with mental retardation: Who and where. Mental Retardation, 32, 173-180.

Gabel, H., & Schwartz Kotasch, L. (1981). Extended families and young handicapped children. Topics in early childhood special education, 1(3), 29-35.

Gabel, H., McDowel, J., & Cerreto, M. (Ed.). (1983). Family adaptation to the handicapped infant. Aspen: Rockvile.

Gallagher, J., Beckman, P., & Cross, A. (1983). Families of handicapped children: Sourse of stress and its amelioration. Exceptional Children, 50, 10-19.

Gallagher, J., Cross, A., & Scharfman, W. (1981). Parental adaptation to a young handicapped child: The father's role. Journal of the Division for Early Childhood, 3, 3-14.

Gallimore, R., Coots, J., Weisner, T., Garnier, H & Guthrie, D. (1996). Family responses to children with early developmental delays II: Accomodation intensity and activity in early and middle childhood. American Journal on Mental Retardation, 101(3), 215-232.

Gallimore, R., Goldenberg, C. N., & Weisner, T. S. (1993). The social construction and subjective reality of activity setting: Implications for community psychology. American Journal of Cmmunity psychology, 21(537-559).

Gardner, J., Scherman, A., Mobley, D., Brown, P., & Schutter, M. (1994). Grandparent's beleifs regarding their role and relationship with special needs grandchildren. Education and Treatment of Children, 21, 185-196.

Garland, C. (Ed.). (1993). Beyond chronic sorrow: A new understanding of family adaptation. Baltimore: Brookes.

Gath, A., & Gumley, D. (1986a). Behaviour problems in retarded children with special reference to Down syndrome. British Journal of psychiatry, 149, 156-161.

Gath, A., & Gumley, D. (1986b). Family background of children with Down syndrome and of children with similar degrees of mental retardation. British Journal of psychiatry, 149, 161-171.

Gelfand, D., & Teti, D. (1990). The effects of maternal depression of children. Clinical Psychology Review, 10, 329-353.

Gelfand, D., Teti, D., Seiner, S. & Jameson, P. (1996). Helping mothers fight depression: Evaluation of a home-based intervention program for depressed mothers and their infants. Journal of clinical child psychology, 25(4), 406-422.

George, J. (1988). Therapeutic intervention for grandparents and extended family of children with developmental delays. American Journal on Mental Retardation, 26(6), 369-375.

German, M., & Maisto, A. (1982). The relationship of a perceived family support system to the institutional placement of mentally retarded children. Education and training in mental retarded, 17, 17-23.

Gerver, J. (1983). A grandparent's view. Children Today, 13-14.

Gill, M., J. (1990). The assessment of social support and individual characteristics as buffer against stress in mothers of handicapped children and nonhandicapped children. Unpublished PhD, The state university of New Jersey, New Jersey.

Glendinning, C. (1986). A single Door. London: Allen Unwin.

Glidden, L. (1993). What do we not know about families with children who have developmental disabilities: questionnaire on resources and stress as a case study. American Journal on Mental Retardation, 97(5), 481-495.

Glidden, L., Valliere, V., & Herbert, S. (1988). Adopted children with mental retardation: positive family impact. Mental retardation, 26, 119-125.

Glidden, L., & Floyd, F. (1997). Disaggregating parental depression and family stress in assessing families of children with developmental disabilities: A multisample analysis. American Journal on Mental Retardation, 102(3), 250-266.

Goldberg, S., Marcovitch, S., MacGregor, D., & Lojkasek, M. (1986). Family responses to developmentally delayed preschoolers: Etiology and the fathers' role. American Journal on Mental Deficiency, 90, 130-139.

Goldberg, S., Morris, P., Simpsons, R., Fowler, R., & Levison, H. (1990). Chronic illness in infancy, and parenting stress: A comparison of three groups of parents. Journal of pediatric Psychology, 15, 347-358.

Goldin, L., & Gershon, E. (Ed.). (1988). The genetic epidemiology of major depression illness (Vol. 7). Washington, DC: American psychiatric Press.

Golombok, S., Brewaeys, A., Cook, R., Giavazzi, M., Guerra, D., Mantovani, A., Vanhall, E., Crosingnani, P., & Dexeus, S. (1996). The european study of assisted reproduction families-family faunctioning and child developmant. Human Reproduction, 11(10), 2324-2331.

Golombok, S., Cook, R., Bish, A. & Murray, C. (1995). Families created by the new reproductive technologies: Quality of parenting and social and emotional development of the children. Child Development, 66, 285-298.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. Journal of Child Psychology, Psychiatry, and Allied Disciplines, 38(5), 581-586.

Goodman, S., Brogan, D., Lynch, M., & Fielding, B. (1993). Social and emotional competence in children of depressed mothers. Child Development, 64, 516-531.

Gorsuch, R. L. (1995). Religious aspects of substance abuse and recovery. Journal of Social Issues, 5(12), 65-83.

Gotlib, I., Whiffen, V., mount, J., Milne, K., & Cordy, N. (1989). Prevalence rates and demographic characteristics associated with depression in pregnancy and the postpartume. Journal of Consulting and Clinical Psychology, 57, 269-274.

Gowen, J., Johnson-Martin, N., Goldman, B., & Applebaum, M. (1989). Feelings of depression and parenting competence of mothers of handicapped and non-handicapped infants: A longitudinal study. American Journal on Mental Retardation, 94(3), 258-271.

Gray, D. E. (1997). High functioning autistic children and the construction of "normal family life". Social Science and Medicine, 44, 1097-1106.

Greenberg, J., Seltzer, M., Krauss, M., & Kim, H. (1997). The differential effects of social support on the psychological well-being of aging mothers of adults with mental illness or mental retardation. Family relations, 46, 383-394.

Griest, D., Forehand, R., Wells, K., & McMahon, R. (1980). An examination of differences between nonclinic and behaviourproblem reffered children and their mothers. Journal of Abnormal Child Psychology, 89, 479-500.

Groomes, D. (1999). The relationship between the stress appraisal process, coping disposition, and level of acceptance of disability. Michigan stste university, Michigan.

Hadaian, A. (1994). Stress and Social support on fathers and mothers of young children with and without disabilities. Early education and development, 5, 226-235.

Hagborg, W. (1989). A comparitive study of parental stress among mothers and fathers of deaf school-age children. Journal of Community Psychology, 17, 220-224.

Hallaham, D., & Kauffman, J. (1991). Exceptional children: Introduction to special education. Englewood Cliffs, NJ: prentice Hall.

Hammen, C. (1991). Depression runs in families: The social context of risk and resiliance in children of depressed mothers. New York: Springer-Verlag.

Hanline, M. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. Psychology in the Schools, 28, 53-59.

Hanneman, R. B., J. (1998). Predicting placement in families who have children with severe handicaps: A longitudinal analysis. American Journal on Mental Retardation, 102(4), 392-408.

Hanson, M., & Hanline, M. (1990). Parenting a child with disability: A longitudinal study of parental stress and adaptation. Journal of Early Intervention, 14, 234-248.

Harns, V. S., & McHale, S. M. (1989). Family life problems, daily caretaking activities, and the psychological well being of mothers of mentally retarded children. American Journal on Mental Retardation, 94, 231-239.

Harris, S., Handleman, J., & Palmer, C. (1985). How parents and grandparents view the autistic child. Journal of Autism and Developmental Disorders, 15, 127-137.

Harris, V., & McHale, S. (1989). Family life problems, daily caregiving activities, and psychological well-being of mothers of mentally retarded children. American Journal on Mental Retardation, 94, 231-239.

Hastings, R. (1997). Grandparents of children with disabilities: A review. International journal of disability, development, and education, 44(4), 329-340.

Hastings, R., & Taunt, H. (2002). Positive perceptions in families of children with developmental disabilities. American Journal on Mental Retardation, 107(2), 116-127.

Hastings, R. P., & Brown, T. (2002). Behaviour problems of children with autism, personal self-efficacy, and mental health. American Journal on Mental Retardation, 107(3), 222-232.

Hastings, R. P., & Brown, T. (2002). Behavioural Knowledge and causal beleifs, and self-effecacy as predictors of special educators' emotional reactions to challenging behaviours. Journal of Intellectual Disability Research, 46(2), 144-150.

Hastings, R. P., & Brown, T. (2002). Coping strategies and the impact of challenging behaviours on special educators' burnout. Mental Retardation, 40(2), 148-156.

Hastings, R. P. (2003). Behavioural adjustment of siblings of children with autism engaged in applied behaviour analysis early intervention programs: the moderating role of social support. Journal of Autism and Developmental Disorders, 33(2), 141-150.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F., & Remington, B. (2004). Coping strategies in mothers and fathers of pre-school age chidren with autsm. Autism, In press.

Hatton, C., & Emerson, E. (2004). The relationship between life events and psychopathology amongst children with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities(17), 109-117.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. Monographs of the Society for Research in Child Development, 66(3, Serial No. 266).

Haversmans, T., & Eiser, C. (1991). Mothers' perceptions of parenting a child with spina bifida. Child, Care, Health, and Development, 17, 259-273.

Hecht, B., Levine, H. & Mastergeorge, A. (1993). Conversational roles of children with developmental delays and their mothers in natural and semi-structured situations. American Journal on Mental Retardation, 97(4), 419-429.

Heller, T. (Ed.). (1993). Self-efficacy coping, active involvement, and caregiver well-being throughout the life course among families of persons with mental retardation. Baltimore: Brookes.

Heller, T., & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. American Journal on Mental Retardation, 96, 163-176.

Heller, T., & Factor, A. (1993). Aging family caregivers: Support resources and changes in Burden and placement desire. American Journal on Mental Retardation, 98(3), 417-426.

Heller, T., & Hsieh, K., & Rowitz, L. (1997). Maternal and Paternal caregiving of persons with mental retardation across the lifespan. Family Relations, 46, 407-415.

Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal caregiving of persons with mental retardation across the life span. Family relations, 46, 407- 415.

Henderson, S., Bryne, D., Duncan-Jones, P., Scott, R., & Adcock, S. (1980). Social relationships, adversity, and neurosis: A study of associations in a general population sample. British Journal of psychiatry, 136, 574-583.

Heppner, P. P., & Krauskopf, C. J. (1987). An information processing approach to personal problem-solving. The Counseling Psychology, 15, 371-447.

Heppner, P. P., & Paterson, C. H. (1982). The development and implications of a personal-solving inventory. Jounal of Counseling Psychology, 29(1), 66-75.

Hill, R. (1949). Families under stress: adjustment to the crisis of war separation and return. New York: Harper Press.

Hirst, M. (1982). Young adults with disabilities and their families. York: University of York.

Hoare, P., Harris, M., Jackson, P., & Kerley, S. (1998). A community survey of children with severe intellectual disability and their families: Psychological adjustment, carer distress and the effect of respite care. Journal of Intellectual Disability Research, 42(3), 218-227.

Hobfoll, S. (1991). Gender differences in stress reactions: Women filling the gaps. Psychology and Health, 5, 95-109.

Hobfoll, S. E. (1998). Stress, Culture, and Community. New York: Plenum Press.

Hodapp, R. (1997). Direct and indirect behavioural effects of different genetic disorders of mental retardation. American Journal on Mental Retardation, 102, 67-79.

Hoekstra-Weebers, J., Jasper, J., Kampas, W. & Klip, C. (2001). Psychological adaptation and social support of parents of pediatric cancer patients: A prospective longitudinal study. Journal of pediatric Psychology, 26(4), 225-235.

Holady, B., Turner-Henson, A., Kanematus, Y., Krulik, T. & Wang, R. (1997). Stress in mothers of chronically ill children: A cross cultural study. Australian Paediatric Nurse, 6(1), 2-9.

Honig, A. S., & Winger, C. J. (1997). A professional support program for families of handicapped preschoolers: Decrease in maternal stress. The Journal of Primary Prevention, 17(3), 285-296.

Hoppner, P. P., Krauskopf, C.J. (1987). An information processing apprach to personal problem-solving. The Counseling Psychology, 15(371-447).

Hops, H., Biglan, A., Sherman, L., Arthur, J., Friedman, L., & Osteen, V. (1987). Home observations of family interactions of depressed women. Journal of Consulting and Clinical Psychology, 55, 341-346.

Hornby, G., & Ashworth, T. (1994). Grandparents' support for families who have children with disabilities. Journal of child and family studies, 3(4), 403-412.

Huang, W., Rubin, S., & Zhang, F. (1998). Correlates of stress level in Chinese mothers of a child with mental retardation. International Journal of Rehabilitation Research, 21(2), 237-240.

Joseph, S. (1999). My son/myself, my mother/myself: Paradoxical relationalities of patriarchal connectivity. In I. S. Joseph (Ed.), Intimate selving in Arab families: Gender, self, and identity (pp. 174-190). Syracuse, NY: Syracuse University Press.

Kaiser, J. S., & Polezynski, J. J. (1982). Educational stress: sources, reactions, preventions. Peabody Journal of Education, 59(2), 127-136.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. Journal of Autism and Developmental Disabilities, 27, 39-57.

Kaufman, A., Adams, J., & Campbell, V. (1991). Permanency planning by older parents who care for adult children with mental retardation. Mental retardation, 29, 293-300.

Kazak, A. (1987). Families with disabled children: Stress and social networks in three samples. Journal of Abnormal Child Psychology, 15, 137-146.

kazak, A., & Marvin, R. (1984). Differences, difficulties and adaptation: Stress and social networks in families with handicapped child. Family Relations, 33, 67-77.

Kearney, P. E., & Griffin, T. ((2001)). Between joy and sorrow: Being a parent of a child with developmental disabilities. Journal of Advanced Nursing, 34(5), 582-592.

Keller, D., W. (1999). Dimensions of parenting stress of mothers and fathers of a school age child with disability. Unpublished PhD, Syracuse University, Syracus.

Khusaifan, S. (2000). Personal and social adjustment in children with hearing disabilities and their peers of normal children in Makkah: A comparative study. Umm Al-Qura University, Makkah.

Kling, K., Seltzer, M., & Ryff, C. (1997). Distinctive late life challenges: Implications for coping and well-being. Psychology and Aging, 12, 288-295.

Knox, M., Parmenter, T., Atkinson, N. & Yazbeck, M. (2000). Family control: The views of families who have a child with an intellectual disability. journal of Applied research in Intellectual disabilities, 13, 17-28.

Koenig, H. G., George, L. K., & Siegler, I.C. (1988). The use of religion and other emotion coping stratigies among older adults. The Gerontologist, 28, 303-310.

Koller, H., Richardson, S., and Katz, M. (1992). Families of children with mental retardation: Comprehensive view from an epidemiological perspective. American Journal on Mental Retardation, 97(3), 315-332.

Konanc, J., & Warren, N. (1984). Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. Family relations, 33, 135-142.

Koopman, C., Hermanson, K., Diamond, S., Angell, K., & Spiegel, D. (1998). Social Support, life stress, emotional adjustment to advanced breast cancer. Psycho-Oncology, 7, 101-111.

Korn, S. J. (1984). Continuities and discontinuities in difficult/easy temperament: Infancy to young adulthood. Merril Palmer Quarterly, 30, 189-199.

Kramer, B. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. Gerontologist, 37, 239-249.

Kramer, B., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiving burden. The Gerontologist, 35, 340-348.

Krauss, M. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. American Journal on Mental Retardation, 97(4), 393-404.

Kronberger, W., & Thompson, R.J. (1992). Psychological adaptation of mothers of children with spina bifida: Association with dimensions of social relationships. Journal of paediatric Psychology, 17(1), 1-14.

Kuster, P., A. (2002). Health outcomes of mothers caring for Ventilator-Assisted Childern at home: The influence of social support, coping, and community resources. Unpublished PhD, University of California, Los Angeles.

Kwai-Sang Yau, M., & Tsang, C. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. The British Journal of Developmental Disabilities, 45, 38-51.

Kwan, C. (2002). Stress and coping among parents of children with autism. Unpublished Master, University of California, Irvine.

LaBorde, P., & seligman, M. (Ed.). (1983). Individual counseling with parents of handicapped children: Rationale and strategies. San Fransisco: Harcourt Brace Jovanovich.

Lamb, M., & Billings, L. (Ed.). (1997). Fathers of children with special needs. New York: Wiley.

Lang, C., Field, T., Pickens, J., Martinez, A., Bendell, D., Yando, R., & Routh, D. (1996). Preschoolers of dysphoric mothers. Journal of child psychology & psychiatry & Allied Disciplines, 37, 221-224.

Larson, D. B., Pattison, E. M., Blazer, D. G., Omran. A. R., & Kaplan, B. H. (1986). Systematic analysis of research on religious variables in four majour psychiatric journals, 1978-1982. American Journal of Psychiatry, 143, 329-334.

Lavee, Y., Sharline, S., & Katz, R. (1996). The effect of parenting stress on marital quality: An integrated mother-father model. Journal of Family Issues, 17, 114-135.

Lavers, S. B. (1998). The grandmother's role in the adjustment of grandchildren. Fournal of child psychology and psychiatry.

Lawrence, E. (1982). The relationship between husband and wife supportiveness and wife's adjustment to motherhood. University of Virginia, Virginia.

Lazarus, R. (Ed.). (1992). Foreword. Seattle: Hogrefe & Huber Publishers.

Lazarus, R., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Lazarus, R. S. (1999). Stress and emotion. New York: Springer.

Lazarus, R. S. (2000). Toward better research on stress and coping. American Psychologist, 55(6), 665-673.

Lazarus, R. S., & Folkman, S. (1991). Coping and emotion. In I. A. M. R. S. Lazarus (Ed.), Stress and Coping (pp. 189-227). New York: Colombia University Press.

Lefcourt, H. (1982). Locus of control: Current trends in theory and research. Hillsdale, NJ: Erlbaum.

Levin, J. S. (1994). Religion and health: Is there an association, is it valid, and is it causal? Social Science and Medicine, 38, 1475-1482.

Levin, R., & Banks, S. (1991). Stress in parents of children with epilipsy. canadian Journal of Rehabilitation, 4(4), 229-238.

Levitt, M., Weber, R., & Clark, M. (1986). Social network relationships as a sources of mental support and well-being. Developmantal psychology, 2, 310-316.

Levy, J., Rimmerman, A., Botuck, S., et al. (1996). The support network of mothers of younger and adult children with mental retardation and developmental disabilities receiving case management. The British Journal of Developmental Disabilities, XLII(82), 24-44.

Lillie, T. (1993). A harder thing than triumph: Roles of fathers of children with disabilities. American Association on Mental Retardation, 31, 438-443.

Longo, D., & Bond, L. (1984). Families of the handicapped child: Research and practice. Family relations, 33, 57-65.

Luterman, D. (1987). Deafness in the family. Boston: College-Hill press.

Lutzky, S., & Knight, B. (1994). Explaining gender differences in caregiving distress: The roles of emotional attentiveness and coping styles. Psychology and Aging, 9, 513-519.

Macias, M. M., Clifford, S. C., Saylor, C. F., & Kren, S. M. (2001). Predictors of parenting stress in families of children with spina bifida. Children's Health Care, 30(1), 57-65.

Madden, S. J., Hastings, R. P., & Hoff, W. V. (2002). Psychological adjustment in children with end stage renal disease: the impact of maternal stress and coping. Care, Health, and Development, 28(4), 323-330.

Magana. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. American Journal on Mental Retardation, 104(5), 466-482.

Mahan, V. S., M. (1999). Cognition versus actions: stress and coping efforts of community college students in west texas, USA. Paper presented at the The european Conference of educational research, Lahti, Finland.

Male, D. (1998). Parent's views about special provision for their child with severe or profound and multiple learning difficulties. journal of Applied research in Intellectual disabilities, 11(2), 129-145.

Mallow, G. E., & Bechtel, G. A. (1999). Chronic sorrow: the experience of parents with children who are developmentally disabled. Journal of Psychological Nursing, 37, 31-35.

Maltiades, H., & Pruchno, R. (2001). Mothers of adult with developmantal disability: Change over time. American Journal on Mental Retardation, 106(6), 548-561.

Marcenko, M. O., & Meyers, J. C. (1991). Mothers of children with developmental disabilities: who shares the burden? Child Development, 40, 186-190.

Marcovitch, S., Goldberg, S., Lojkasek, M., & MacGregor, D. (1987). The concept of difficult temperament in the developmentally disabled preschool child. Journal of Applied Developmental Psychology, 8, 151-164.

Mardiros, M. (1985). Role alternations of female parents having children with disabilities. Canada's Mental Health, 33, 24-26.

Margalit, M., & Ankonina, D. (1991). Positive and negative effect in parenting disabled children. Counseling psychology quarterly, 4(4), 289-299.

Markus, E. J. (1990). Does it pay for a woman to work outside her home? Journal of Comparative Family Studies, 21(3), 397-411.

Marschark, M. (1993). Psychological development of deaf children. New York: Oxford university press.

Marsella, A. J., & Kameoka, V. A. (1989). Ethnocultural issues in the assessment of psychopathology. In S. Wetzeler (Ed.), Measuring mental illness in psychometric assessment for clinicians (pp. 231-256). Washington D.C.: American Psychiatric press.

Marsella, A., & Schever, A. (Ed.). (1987). Coping, culture and healthy human developmant. Beverly Hills: CA-Sage.

Marsh, D. (1992). Families and mental retardation: New directions in professional practice. New York: Praeger.

Marshall, G. (1998). Oxford dictionary of sociology. Oxford: Oxford University Press.

Mash, E. J., C. (1983). Parental perceptions of child behavioural problems, parenting self-esteem, and mothers reported stress in younger and older hyperactive and normal children. Journal of Councelling and Clinical Psychology, 51, 86-99.

Mastroyannopulou, K., Stallard, P., Lewis, M. & Lenton, S. (1997). The impact of childhood non-malignant life-threatening illness on parents: Gender differences and predictors of parental adjustment. Journal of child psychology and psychiatry, 38(7), 823-829.

Mathew, A. (Ed.). (1993). Attention and memory for threat in anxiety. Seattle: Hogrefe & Huber.

McBride, B. A. (1989). Stress and fathers' parental competence: implications for family life and parent educators. Family Relations, 38, 385-389.

McConachie, H. (1986). Parents & young mentally handicapped children. A review of research issues (Vol. Croom Helm). London.

McCubbin, H., & Paterspn, J., (Ed.). (1983). Family stress adaptation to crises: A double ABCX model of family behaviour. New York: Haworth Press.

McCubbin, H., Cauble, A., Comeau, J., Patterson, J., & Needle, R. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42, 855-871.

McCubbin, H., McCubbin, M., Patterson, J., Cauble, A., Wilson, L., & Warwick, W. (1983). CHIP-Coping Health Inventory for parents: An assesement of parental coping patterns in the care of the chronically ill child. Journal of Marriage and the Family, 45(2), 359-369.

McCubbin, M., & Hauang, S. (1989). Family strengths in the care of handicapped children: Targets of intervention. Family relations, 38, 436-443.

McDonald, T. P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological prespective. American journal of Orthopsychiatry, 69(1), 100-109.

McKinney, B., & Peterson, R. (1987). Predictors of stress in parents of developmentally disabled children. Journal of pediatric Psychology, 12, 133-149.

Meager, I. M., J. (1996). Group treatment for postpartume depression: A pilot study. Australian and New Zealand journal of psychiatry, 30(852-860).

Menaghan, E., & Parcel, T. (1990). Parental employment and family life: Research in the 1980's. Journal of Marriage and the Family, 52, 1079-1098.

Meyerson, R. (Ed.). (1983). Family and parent group therapy. San Fransisco: Harcourt Brace Jovanovich.

Milgram, N., & Artzil, M. (1988). Parenting stress in raising autistic children. Journal of Autism and Developmental Disabilities, 18, 415-424.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? Gerontologist, 32, 498-507.

Miller, B. C., & Sollie, D. L. (1980). Normal stress during the transition to parenthood. Family Relations, 29, 459-465.

Miltiades, H. B., & Pruchno, R. (2001). Mothers of adults with developmental disability: Chande over time. American Journal on Mental Retardation, 106(6), 548-561.

Mink, I. T. (1990). Building a family classification system: Families with mentally retarded children. In W. I. Fraser (Ed.), Key issues in mental retardation research (pp. 209-221). New York: Routledge.

Minnes, P. (1988). Family resources and stress associated with having a mentally retarded child. American Journal on Mental Retardation, 93, 184-192.

Mirfin-Veitch, B., Bray, A. & Watson, M. (1996). They really do care: Grandparents as informal support sources for families of children with disabilities. New Zealand journal of disability studies, 2, 136-148.

Mirfin-Veitch, B., Bray, A. & Watson, M. (1997). We're just that sort of family: Intergenerational relationships in families including children with disabilities. Family relations, 46, 305-311.

Mirza, H. (1993). Parents' attitudes towards their multiple disabled children. King Saud University, Rhiyads.

Mitchell, G., & Hastings, R. (2001). Coping, Burnout, and emotion in staff working in community services for people with challenging behaviours. American journal on Mental Retardation, 106(5), 448-459.

Mitchell, R., & Trickett, E. (1980). Task force report: Social networks as mediators of social support. Community Mental Health Journal, 16, 27-43.

Molsa, P. M., I. (1985). The mentally handicapped child and family crisis. Journal of mental deficit research, 29, 309-314.

Moos, R. H., & Schaefer, J.A. (1984). The crisis of physical illness: An overview and conceptual approach. In R. H. Moos (Ed.), Coping with physical illness 2:New prespective (pp. 2-25). New York: Plenum Press.

Moos, R., & Moos, B. (1981). Family Enviroment scale. Palo Alto, CA: Counselling psychology press.

Mouton, P. Y., & Turna, J. M. (1988). Stress, locus of control, and role satisfaction in clinic and control mothers. Journal of Clinical Child Psychology, 17(3), 217-224.

Mullens, P., A. (1991). Child temperament, and its relationship to stress in mothers of 1-3 year-old children with cerebral palsy. Unpublished PhD, University of Washington, Washington.

Nagi, M. (1983). Trends in Moslem fertility and the application of the demographic translation model. Social Biology, 30(3), 245-262.

Nakagawa, M., Teti, D. & Lamb, M. (1992). An ecological study of child-mother attachment among Japanese Sojourners in the United States. Developmental psychology, 28(4), 584-592.

Narchi, H., & Kulaylat, N. (1996). Congenital malformations: Are they more prevalent in population with high incidence of consanguineous marriages? Annals of Saudi Medicine, 17(2), 254-256.

Nihira, K., Meyers, C., & Mink, I. (1980). Home environment, family adjustment and the development of mentally retarded children. Applied Research in Mental Retardation, 1, 5-24.

Nikapota, A. D. (1986). Parent's perceptions of needs for the care of their retarded children in Siri Lanka. In J. M. Berg (Ed.), Science and service in mental retardation (pp. 396-402). New York: Methuen.

Nixon, C. S., G. (1993). Group cognitive-behavioural treatment for excessive parental self-blame and guilt. American Journal on Mental Retardation, 97(6), 665-672.

Nolan, T., Desmond, K., Herlich, R. & Hardy, S. (1986). Knowledge of Cystic fibrosis in patients and their parents. Paediatrics, 77, 229-235.

Nolen-Hoeksema, S. (1990). Sex differences in depression. Stanford, CA: Stanford University Press.

Noojin, A. B. (1997). Stress, self appraised problem-solving ability, coping, and adjustment in mothers of children with physical disabilities. Unpublished PhD, University of Alabama, Birmingham.

Nyrope, R. (1984). Saudi Arabia: A country study: U.S Government.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. Journal of Intellectual Disability Research, 45, 535-543.

Ong, L., Afifiah, A., & Lye, M. (1998). Parenting stress among mothers of Malaysian children with cerebral palsy: Predictors of child-parent-related stress. Annals of Tropical Paediatrics, 18(4), 301-307.

Orr, R., Cameron, S. & Day, D. (1991). Coping with stress in families with children who have mental retardation: An evaluation of the double ABCX model. American Journal on Mental Retardation, 95(4), 444-450.

Orr, R. R., Cameron, S.J., Dobson, L. A., & Day, D. M. (1993). Age-related changes in stress experienced by families with a child who has developmental delays. Mental Retardation, 51(3), 171-176.

Ostberg, R. D., & Hagekull, B. (2000). A structural modelling approach to the understanding of parenting stress. Journal of Clinical Child Psychology, 29(4), 615-625.

Palfrey, J. S., Walker, D. K., Butler, J. A., & Singer, J. (1989). Patterns of responses in families of chronically disabled children: An assessment in five metropolitan school districts. American journal of Orthopsychiatry, 59(1), 94-104.

Pargament, K. (1997). The psychology of religion and coping: Theory, research and practice. New York: Guilford.

Parke, R. (Ed.). (1995). Fathers and families: Vol. 3. Status and social conditions of parenting (Vol. Relbaum). Mahway, Newjersey.

Parry, G. (1986). Paid employment, social stress, and mental health in working class women with young children. Unpublished PhD.

Paterson, R., & Neufeld, R. (Ed.). (1989). The stress response and parameters of stressful situations. New York: Wiley.

Patterson, G. (1980). Mothers: The unacknowledged victims. Monographs of the society for Research in Child Development, 45, 1-54.

Patterson, J., M. & Garwick, A., W. (1994). The impact of chronic illness on families: A family systems perceptive. Annals of Behavioral Medicine, 16(2), 131-142.

Patterson, J. M. (1988). Families experiencing stress: the family adjustment and adaptation response model. Family Systems Medicine, 6(2), 202-237.

Pearlin, L. I., Lieberman, M., A., Menaghan, E.G. & Mullan, J.T. (1981). The stress process. Journal of Health and Social Behaviour, 22, 337-356.

Pearlin, L. I., Mullan, J.T., Semple. S.J, & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583-591.

Pearson, D., L., Loveland, K., et al.,. (2000). Behavioural adjustment and maladjustment in mental retardation: Comparison of children with and without ADHD. American Journal on Mental Retardation, 105(4), 236.

Perczek, R., Carver, C., Price, A. (2000). Coping, mood, and aspect of personality in Spanish Translation and evidence of convergence with English versions. Journal of Personality Assessment, 74, 63-87.

Peshawaria, R., Menon, D., Ganguly, R., Roy, S., Rajam, P., & Cupta, S. (1998). A study of facilitators and inhibitors that affect coping in parents of children with mental retardation in India. Asia Pacific Disability Rehabilitation Journal, 9(1).

Peterson, P. (1984). Effects of moderator variables in reducing stress outcomes in mothers of children with handicapped. Journal of psychosomatic, 28, 337-344.

Pit-Ten Cate, I., M. (2003). Family adjustment to disability and chronic illness in children. Unpublished PhD, University of Southampton, Southampton.

Piven, J., Chase, G., Landa, R., Wzorek, M., Gayle, J., Cloude, D., & Folstein, S. (1991). Psychiatric disorders in parents of autistic individuals. Journal of the American Academy of Child and Adolescent Psychiatry, 30, 471-478.

Pless, I. B., & Pinkerton, P. (1975). Chronic childhood disorder: Promoting patterns of adjustment. London: Henry Kimpton Publisher.

Prieto, A. (1992). A method for translation of instruments to other languages. Adult education Quarterly, 43(1), 1-14.

Pruchno, R., & Resch, N. (1989). Husband and wives as caregivers: Antecedents of depression and burden. Gerontologist, 29, 159-165.

Pruchno, R. P., J. (1999). Effects of formal and familial residintal plans for adults with mental retardation on their aging mothers. American Journal on Mental Retardation, 104(1), 38-52.

Ptacek, J., Smith, R., & Dodge, K. (1994). Gender differences in coping with stress: When stressor and appraisals do not differ. Personality and Social Psychology Bulletin, 20, 421-430.

Quine, L., & Pahl, J. (Ed.). (1986). Parents with severely mentally handicapped children: Marriage and the stress of caring. Rugby: National marriage guidance council.

Quine, L., & Pahl, J. (1989). Stress and coping in families caring for a child with severe mental handicapped: A longitudinal study. Canterbury: Institute for social and applied psychology and centre for health service studies, University of Kent at Canterbury.

Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transaction model of coping. Journal of community and Applied Social Psychology, 1(1), 57-70.

Regan, A. S., J. (1989). Severe mental handicap: What do parents think? Handicap Research, 2(1), 73-85.

Reid, R. (1995). Assessment of ADHD with culturally different groups: The use of behaviour rating scales. School Psychology review, 24(4), 537-560.

Reiss, S., Levitan, G., & Szyszko, J. (1982). Emotional, Disturbance and mental retardation: Diagnostic overshadowing. American Journal of Mental Deficiency, 86, 567-574.

Reitman, D., Currier, R., Stickle, T. (2002). A critical evaluation of the Parenting Stress Index-Short Form (PSI-SF) in a heath start population. Journal of Clinical and Adolescent Psychology, 31(3), 384-392.

Richardson, S., Katz, M., & Koller, H. (1986). Sex differences in number of children administratively classified as mildly mentally retarded: An epidemiological review. American Journal of Mental Deficiency, 91(3), 250-256.

Richman, N., Stevenson, J., & Graham, P. (Ed.). (1985). Sex differences in outcome of pre-school behaviour problems: John Wiley & Sons.

Ring, H., Tshuva, M., Ronen, A., Dynia, A. & Eldar, R. (1998). Quality of care on a stroke rehabilitation ward: The use of urinary incontinence as tracer. International journal of rehabilitation research, 21, 241-245.

Roach, M., Orsmond, G. & Barratt, M. (1999). Mothers and Fathers of children with Down syndrome: Parental stress and involvement in childcare. American Journal on Mental Retardation, 104(5), 422-436.

Robins, L., Helzer, J., Weissman, M., Orvaschel, H., Gruenberg, E., Burke, J. & Regier, D. (1984). Lifetime prevalence of specific psychiatric disorders in three cities. Achieves of general psychiatry, 41, 949-958.

Rodrigue, J., Morgan, S., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. Journal of clinical child psychology, 19, 371-379.

Rojahn, J., Tasse, M. & Sturmey, P. (1997). The stereotyped behaviour scale for adolescents and adults with mental retardation. American Journal on Mental Retardation, 102(2), 137-146.

Rolland, J. S. (1994). Families, illness, and disability: An integrative treatment model: Harper Collins publishers.

Ross, D. M., & Ross, S. A. (1984). The importance of type of question, psychological climate and subject set. Pain, 19, 71-79.

Ross, O. A. (1980). Psychological disorders of children. New York: McGraw-Hill.

Rough, A. B. (1985). Family in contemporary Egypt. Cairo: The American University Cairo Press.

Rousy, A., Best, S., & Blacher, J. (1992). Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities. American Journal on Mental Retardation, 97(1), 99-109.

Russel, A. (1997). Individual and family factors contributing to mothers' and fathers' positive parenting. International Journal of Behavioural Development, 21, 111-132.

Rutter, M. (1987). Psychological resilience and protective mechanisms. American journal of Orthopsychiatry, 57, 316-331.

Rutter, M., & Garmezy, N. (Ed.). (1983). Developmental psychology. New York: Wiley.

Ryde-Brandt, B. (1991). Now it is time for your child to go to school, how do you feel? International journal of Disability, Development, and Education, 38, 45-58.

Salisbury, C. (1987). Stressors of parents with young handicapped and nonhandicapped children. Journal of the Division for Early Childhood, 11, 154-160.

Salter, M. (1986). Modification of mothers- child interaction process in families with children at-risk for mental retardation. American Journal of Mental Deficiency, 91(3), 257-267.

Sandler, A. (1998). Grandparents of children with disabilities: A closer look. Education and training in mental retardation and developmental disabilities, 33(4), 350-356.

Sandler, A., Warren, S. & Raver, S. (1995). Grandparents as a source of support for parents of children with disabilities: A brief report. Mental retardation, 33(4), 248-250.

Schell, G. (1981). The young handicapped child: A family perspective. Topics in Early Childhood Special Education, 1, 21-27.

Scheneider, H. (2000). Saudi Intermarriage have genetic costs. Washington post Foreign service, 16, A01.

Scherman, A., Gardner, J., Brown, P. & Schutter, M. (1995). Grandparents' adjustment to grandchildren with disabilities. Educational Gerontology, 21, 261-273.

Schild, S. (1982). Beyond diagnosis: Issues in recurrent counceling of parents of the mentally retarded. Social Work in Health Care, 8, 81-93.

Schilmoeller, G. B., M. (1998). Integrational support in families with disabilities: Grandparents' perspective. Family in society, Sep-Oct, 465-476.

Schreurs, K. M., De Rider, D. T., & Bensing, J. M. (1999). A one-year study of coping, social support and quality of life in Parkinson's Disease (pp. 109-120). Malaysis: The Harwood Academic Publishers imprint.

Scott, B., Atkinson, L., Minton, H., & Bowman, T. (1997). Psychological distress of parents of infants with Down syndrome. American Journal on Mental Retardation, 102(2), 161-171.

Scott, R., Sexton, D., Thompson, B. & Wood, T. (1989). Measurement characteristics of a short form of the questionnaire on resources and stress. American Journal on Mental Retardation, 94, 331-339.

Seligman, M. (1991). Grandparents of disabled grandchildren: Hopes, fears, and adaptation. Families in Society, 72, 147-152.

Seligman, M., Goodwin, G., Paschal, K., Applegate, A. & Lehman, L. (1997). Grandparents of children with disabilities: perceived levels of support. Education and training in mental retardation and developmental disabilities, Dec., 293-303.

Seligman, M. D., R. (1989). Ordinary families, Special children. New York: The Guilford press.

Seltzer, M., & Krauss, M. (1989). Aging parents with mentally retarded children: Family risk factors and sources of support. American Journal on Mental Retardation, 94, 303-312.

Seltzer, M., Greenberg, J., & Krauss, M. (1995). A comparison of coping strategies of aging mothers of adult with mental illness or mental retardation. Psychology and Aging, 10, 64-75.

Seltzer, M., Greenberg, J., & Krauss, M. (1997). Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. Family relations, 46, 13-22.

Seltzer, M., Greenberg, J., Floyd, F., Pettee, Y. & Hong, J. (2001). Life course impacts of parenting a child with a disability. American Journal on Mental Retardation, 106(3), 265-286.

Serbper, A., Devellis, R. & Boehlecke, B. (1994). Cross-cultural translation: Methodology and validation. Journal of Cross Cultural Psychology, 25, 501-524.

Shah, Q., & Sonuga-Barke, E. (1995). Family structure and the mental health of Pakistanian Muslim mothers and their children living in Britain. British Journal of Clinical Psychology, 34, 79-81.

Shapiro, J., & Tettle, K. (1990). Maternal adaptation to child disability in a Hispanic population. Family Relations, 39, 179-185.

Sharawi, Z. A. (1987). The industrial Impact of the family structure in Saudi Arabia: A field study in the city of Dammam. Unpublished M.Ed, King Abdulaziz University, Jeddah.

Shelton, B. (1990). The distribution of household tasks: Does wife's employment status make a difference? Journal of Family Issues, 11, 115-135.

Shin, J. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. Mental retardation, 40(2), 103-118.

Simons, R. (1987). After the tears: Parents talk about raising a child with a disability. New York: Harcourt Brace Jovanovich.

Singer, G. H., & Irvin, L. K. (1989). Family caregiving, stress, and support. In G. H. Singer (Ed.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes.

Singer, L., Salvator, A., Guo, S. (1999). Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. Journal of American medical association, 28(9), 799-805.

Singer, L., Song, L., Hill, B. & Jaffe, A. (1990). Stress and depression in mothers of failure-to-thrive children. Journal of paediatric Psychology, 15(6), 711-720.

Singhi, P. D., Goyal, L., Pershad, D., Singhi, S., & Walia, B. N. (1990). Psycosocialproblems in families of disabled children. British Journal of Medical Psychology, 63, 173-182.

Sloper, P. (1996). Needs and responses of parents following the diagnosis of childhood cancer. Child: Care, Health, and Development, 22, 187-202.

Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. Journal of child psychology and psychiatry, 34, 167-188.

Smith, G. (1997). Aging families of adults with mental retardation: Patterns and correlates of service use, needs, and knowledge. American Journal on Mental Retardation, 102(1), 13-26.

Snaith, R. T. (1985). Rating scales for depression and anxiety: A currentperspective. British Journal of Clinical Pharmacology, 19, 17-21.

Sofi, J. (1992). Status of disabled person and programs of available services in Saudi Arabia, Proceeding of the conference on the capital and needs of disabled persons in the ESCWA region. Amman, Jordan, United Nation.

Soliday, E., Mc-Cluskey-Fawcett, K. & O'Brien, M. (1999). Postpartume affect and depressive symptoms in mothers and fathers. American journal of Orthopsychiatry, 69(1), 30-38.

Solis, M., & Abidin, R. (1991). The Spanish version Parenting Stress Index: A psychosometric study. Journal of clinical child psychology, 20, 372-378.

Sonnek, I. M. (1986). Grandparents and the extended family of handicapped children. In R. V. Fewell, P. (Ed.), Families of handicapped children, needs and supports across the life span: pro.ed.

Sonnuga-Barke, E., Thompson, M. & Balding, J. (1993). Everyday beliefs about sources of advice for the parents of difficult children. Child care and health developmant, 19, 251-260.

Sonuga-Barke, E., Mistry, M., & Qureshi, S. (1998). The mental health of Muslims mothers in extended families living in Britain: The impact of integrational disagreement on anxiety and depression. British Journal of Clinical Phsychology, 37, 399-408.

Spaulding, R., & Morgan, S. (1986). Spina bifida children and their parents: A population prone to family dysfunction? Journal of paediatric Psychology, 11, 359-374.

Sperber, A., Devellis, R. & Boehlecke, B. (1994). Cross-cultural translation: Methodology and validation. Journal of Cross Cultural Psychology, 25(4), 501-524.

Spina Bifida, 95% of mothers do not take Folic Acid. (2003, 3 January). Riyadh Daily.

Stalker, K. (1996). Developments in short-term care: Breaks and opportunities. London and Bristol, Pennsylvania: Jessica Kingsley Publishers.

The Statistical indicators. (2000). (Vol. 25). Riyadh: Ministry of planning, Central department of statistics, kingdom of Saudi Arabia.

Statistical yearbook. (2000). (Vol. 36). Riyadh: Kingdom of Saudi Arabia, Ministry of planning, Central department of statistics.

Stein, R., & Jessop, D. (1982). A noncategorical approach to chronic childhood ilness. Public Health Reports, 97, 354-362.

Stevenson, J. (1993). Multivariate statistics: the use of factor scores in psychiatric research. Nord Journal of Psychiatry, 47, 169-178.

Stevenson., J. (1989). Multivariate statistics. I. Using different types of multivariate statistics to identify types of psychopathology. Nord Psykia Tidsskr, 43, 317-323.

Stinnett, H. D., J. (1985). Secrets of strong families. Boston: Little Brown & Co.

Stratton, P. (Ed.). (1990). Parents' conceptualisation of children as the organiser of culturally structured enviroments: John Wiley.

Struening, E. L., Stueve, A., Vine, P., Kreisman, D. E., Link, B. G., & Herman, D. B. (1995). Factors associated with grief and depressive symptoms in caregivers of people with serious mental illness. Research in Community and Mental Health, 8, 91-124.

Styles, B. (1986). The unseen handicap. Emotional First aid: A journal of Crisis Intervention, 3(2), 19-22.

Subotsky, F. B., G. (1990). Customer views at community child guidane clinic. ACCP Newsletter, 12, 8-12.

Sueltze, M., & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded person. American Journal on Mental Retardation, 86, 267-274.

Summers, J., Behr, S., & Turnbull, A. (Ed.). (1989). Positive adaptation and coping strengths of families who have children with disabilities. Baltimore: Paul H. Brookes Publishing Co.

Sutherland, S. (1995). The Macmillan Dictionary of psychology. Basingstoke: The Macmillan Press LTD.

Taha, F. (1993). Encyclopaedia of psychology and psychoanalysis. Kuwait: Suad Al-Subah Press.

Taibi, A. (1997). Hereditary diseases in Arab world: Oxford University Press.

Tam, K., Chan, Y. & Wong, C. (1994). Validation of the Parenting Stress Index among Chinese mothers in Hing Kong. Journal of Community Psychology, 22(3), 211-223.

Tasse, M., Lecavalier, L. (2000). Comparing parent and teacher ratings of social competence and problem behaviours. American Journal on Mental Retardation, 105(4), 252-259.

Tavormina, J., Boll, T., Dunn, N., Luscomb, R., & Taylor, J,. (1981). Psychosocial effects on parents of raising a physically handicapped child. Journal of Abnormal Child Psychology, 9, 121-131.

Taylor, S. (1983). Adjustment to threatinig events: A theory of cognitive adaptation. American Psychologist, 38, 624-630.

Taylor, S., & Brown, J. (1988). Illusion and well-being. Some social psychological contributions to a theory of mental health. Psychological Bulletin, 103, 193-210.

Thoits, P. (1995). Stress, Coping, and social support processes: Where are we? What next? Journal of Health and Social Behaviour((extra issue)), 53-79.

Thome, M., & Alder, B. (1999). A telephone intervention to reduce fatigue and symptom distress in mothers with difficult infants in the community. 1999, 29(1), 128-137.

Thompson, R. J., Gil, K. M., Burbach, D. L., & Keith, B. R. (1993). Psychological adjustment of mothers of children and adolescents with sickle cell disease: the role of stress, coping methods, and family functioning. Journal of pediatric Psychology, 18, 549-559.

Thompson, R. J., Gil, K. M., Burbach, D. L., & Keith, B. R. (1993). Role of child and maternal process in the psychological adjustment of children with sickle cell disease. Journal of Consulting and Clinical psychology, 61(469-474).

Thompson, R. J., Gil, K.M., Gustafson, K.E, George, L. K., Keith, B. R, Spock, A., & Kinney, T. R. (1994). Stability and change in the psychological adjustment of mothers of children and adolescents with cysitc fibrosis and sicle cell disease. Journal of pediatric Psychology, 19(2), 171-188.

Thompson, R. J., Zeman, J.L, Fanurik, D., & Sirotkin-Roses, M. (1992). The role of parent's stress and coping and family functioning in parent and child adjustment to duchenne muscular dystrophy. Journal of Clinical Psychology, 48(1), 11-19.

Tiedje, L., & Darling-Fisher, C. (1993). Factors that influence fathers' participation in child care. Health Care for Women International, 14, 99-107.

Tisher, M., Tonge, B., & Horne, D. (1994). Childhood depression, stressors and parental depression. Australian and New Zealand journal of psychiatry, 28, 635-641.

Triandis, H., & Brislin, R. (1984). Cross cultural psychology. American Psychologist, 39(9), 1006-1016.

Trivette, C., Dunst, C., Deal, A., Hamer, A., & Propst, S. (1990). Assessing family strengths and family functioning style. Topics in Early Childhood Special Education, 10, 16-35.

Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. Family Relations, 39, 292-297.

Trute, B., & Hauch, C. (1988 b). Social network attributes of families with positive adaptation to the birth of developmentally disabled child. Canadian Journal of Community Mental Health, 7, 5-16.

Trute, B., & Hauch, C. (1988a). Building on family strength: A study of families with positive adjustment to the birth of a developmentally disabled child. Journal of Marital and Family Therapy, 14, 185-193.

Tsang, S., Tsang, S., Chan, E., & Lee, C. (1992). Stress of parents with normal and special preschool children: A comparison study. Bulletin of the Hong kong Psychological Society, 28, 63-79.

Turnbull, A. (Ed.). (1985). From professional to parent: A startling experience. Columbus, OH: Charles E. Merrill.

Turnbull, A., Blue-Banning, M., Behr, S., & Kerns, G. (Ed.). (1986a). Family research and intervention: A value and ethical examination. Baltimore: Paul H. Brookes Publishing Co.

Turnbull, A., Brotherson, M., & Summers, J. (Ed.). (1984). The impact of deinstitutionalization on familes: A family system approach. Baltimore, MD: Paul H. Brooks.

Turnbull, A., Brotherson, M., Summers, J., & Turnbull, H. (Ed.). (1986b). Fathers of disabled children. New York: Guilford Press.

Turner, S., Hatton, C., Shah, R., Stanfield, J., & Rahim, N. (2004). Religious Expression amongst adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 161-171.

Turner, R. J., & Marino, F. (1994). Social support and social structure: a descriptive epidemiology. Journal of Health and Social Behaviour, 35, 193-212.

Vaccari, C. Marschark, M. (1997). Communication between parents and deaf children: Implications of social-emotional development. Journal of child psychology and psychiatry, 38(7), 793-801.

Vadasy, P., & Fewell, R. (Ed.). (1986). Mothers of deaf-blind children. Austin, TX: Pro-Ed.

Vadasy, P., Fewell, R., & Meyer, D. (1986). Grandparents of children with special needs: Insights into their experiences and concerns. Journal of the Division for Early Childhood, 10, 36-44.

Valachopoulos, G. (1991). Changes in family structure in the Middle East with special reference to Jordan and Saudi Arabia. Reading University, Reading.

Vallerand, R. (1989). Toward a methodology of cross-cultural validation of psychology questionnaires-Implication for research in French. Journal of Canadian Psychology, 30, 662-680.

Van Riper, M., Ryff, C., & Pridham, K. (1992). Parental and family well-being in families of children with Down syndrome: A comparative study. Research in Nursing ans Health, 15, 227-235.

Van Zuuren, F. D., R. (1999). Coping style and self-reported health promotion and diseases detection behaviour. British journal of psychology, 4(81-89).

Vandell, D. (2000). Parents, peer groups, and others socializing influences. Developmental phsychology, 36(6), 699-710.

Varni, J., & Wallander, J. (Ed.). (1988). Pediatric chronic disabilities: Hemophilia and spina bfida examples. New York: Guildford press.

Varni, J., Katz, E., Colegrove, R., & Dolgin, M. (1996). Family functioning predictors of adjustment in children with newly diagnosed cancer: A prospective analysis. Journal of child psychology and psychiatry, 37(321-328).

Vedhara, K., Addy, L. & Wharton, L. (2000). The role of social support as a moderator of the acute stress response: In situ versus empirically-derived associations. Psychology and health, 15, 297-307.

Vedhare, S. N., K. (88). (1996). Psychosocial vulnerability to stress. Journal of psychosomatic research, 41, 255-267.

Veisson, M. (2000). A comparative study between the siblings of mentally retarded children and controll group in Estonia. International Journal of Psychology, 35, 151.

Viera, S. (1994). Characteristics of stress in parents of children with chronic diseases and in parents of children with emotional problems. Analyse psychology, 12, 2-3.

Viera, S., Ataide, S. & Joao, P. (1996). Parental stress in parents of children with obesity and with chronic renal disease. Analyse psychology, 14, 231-243.

Vingerhoets, A., & Van Heck, G. (1990). Gender, coping, and psychosomatic symptoms. Psychological Medicine, 20, 125-135.

Vitaliano, P., Maiuro, R., Russo, J., & Becker, J. (1987). Raw versus relative scores in the assessment of coping strategies. Journal of Behavioural Medicine, 10, 1-18.

Voigtman, J., L. (2002). Learning to suffer: Pain response in a community of saudi Arabian children with sickle cell disease. Unpublished PhD, university of Arizona.

Wagner, D. (1986). Child development research and the third world: A future natural interest? American Psychologist, 41(3), 298-301.

Waisbern, S. (1980). Parents' reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency, 84(4), 345-351.

Walden, T., Knieps, L. & Baxter, A. (1991). Contingent provision of social referential information by parents of children with and without developmental delays. American Journal on Mental Retardation, 96(6), 177-187.

Walker, L., Ortiz-Valdes, J., & Newbrough, J. (1989). The role of maternal employment and depression in the psychological adjustment of chronically ill mentally retarded and well children. Journal of pediatric Psychology, 14, 357-370.

Wallander, J., Varni, J., Babani, L., Tweddle Banis, H, & Wilcox, T. (1989). Family resources as a resistance factors for psychological maladjustment in choronically ill and handicapped children. Journal of pediatric Psychology, 14, 157-173.

Wallander, J. L. (1989). The social environment and the adaptation of mothers of physically handicapped children. Journal of paediatric Psychology, 14(3), 371-387.

Wallander, J. L. (1993). Special section editorial: Current research on paediatric chronic illness. Journal of paediatric Psychology, 18(1), 7-10.

Wallander, J. L., & Varni, J. W. (1992). Adjustment in children with chronic physical disorders: programmatic research on a disability-stress-coping model. In A. M. L. G. L. J. Siegel (Ed.), Stress, coping and child health. Advances in pediatric psychology. New York: USA: Guilford Press.

Wallander, J. L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. Journal of child Psychology and psychiatry, 39, 29-46.

Warfield, M. E. (2001). Employment, parenting, and well-being among mothers of children with disabilities. Mental Retardation, 39, 297-309.

Weber, G., & Parker, T. (Ed.). (1981). A study of family and professional views of the factors affecting family adaptation to a disabled child. Lincoln, N.E.: University of Nebraska Press.

Weinhouse, D., Weinhouse, M., & Nelson, G. (1992). Stress factors in families of young children with exceptional educational needs. School Psychology International, 13, 51-59.

Weisman, M., & Boyd, J. (1983). The epidemiology of affective disorders: Rates and risk factors (Vol. 2). Washington, DC: American Psychiatry Press.

Weisner, T., Beizer, L., & Stolze, L. (1991). Religion and families of children with developmental delays. American Journal on Mental Retardation, 95(6), 647-662.

Werner, E., & Smith, R. (1992). Overcoming the odds: High-risk children from birth to adulthood. Ithaka: New York: Cornell University Press.

Wertsch, J. Y., J. (1987). Contextualizing the investigator: The case of developmental Psychology. Human Developmant, 30, 18-31.

White, N., & Hastings, R. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 181-190.

Wilker, L. (1981). Chronic stresses in families of mentally retarded children. Family Relations, 30, 281-288.

Wilker, L. (1986). Family stress theory and research on families of children with mental retardation. In P. M. V. In J. J. Gallagher (Ed.), Families of handicapped persons: Research, programs, and policy issues. Baltimore: Brookes Publishing Co.

Wilker, L. (1986). Periodic stresses in families of children with mental retardation. American Journal of Mental Deficiency, 90, 703-706.

Wilker, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of adjutment of parents of mentally retarded children. American journal of Orthopsychiatry, 51(1), 63-70.

Wilker, L., Wasow, M., & Hatfield, E. (1983). Seeking strengths in families of developmentally disabled children. Social Work, 28, 313-315.

Wille, D. (1995). The 1990's: Gender differences in parenting roles. Sex Roles, 33, 803-817.

Willner, P. G., R. (2001). Mediation of depression by perceptions of defeat and entrapment in high-stress mothers. British Journal of Medical Psychology, 74, 473-485.

Willoughby, J., & Glidden, L. (1995). Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities. American Journal on Mental Retardation, 99, 399-406.

Wilson, L. (2002). Risk and Resistance and adjustment in maternal caregivers of children with serious mental disorders. Unpublished PhD, The Fielding Graduate Institute.

Wilson, M. N. (1986). The black extended family: an analytical consideration. Developmantal Psychology, 22(2), 246-258.

Wilton, K. R., J. (1986). Stress levels in families with intellectually handicappes preschool children and families with nonhandicapped preschool children. Journal of mental deficiency research, 30, 163-169.

Wing, L. (1985). Autistic children. New York: Brunner/Mazel.

Winzer, M. (1990). Children with exceptionalities: a Canadian perspective. Toronto: Prentice Hall.

Wishart, M., Bidder, R., & Gray, D. (1981). Parent's reports of family life with a developmentally delayed child. Child: Care, Health, and Development, 7, 267-279.

Wishner, J. (2002). Parenting stress: developmental trends and individual differences. Unpublished PhD, Claremount graduate university, California.

Wolf, L., & Goldberg, B. (1986). Autistic children grow up: An eight to twenty-four year follow-up study. Canadian Journal of psychiatry, 31(550-556).

Wolf, L., Noh, S., Fisman, S., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. Journal of Autism and Developmental Disorders, 19(1), 157-166.

Wortman, C. (1984). Social Support and the cancer patient: Conceptual and methodological issues. Cancer, 53, 2339-2360.

Yuk-Ki Chen, T. (1997). Stress appraisal and social support of Chinese mothers of adult children with mental retardation. American Journal on Mental Retardation, 101(5), 473-482.

Zahn-Waxler, C., Iannotti, R., Cummings, E., & Denham, S. (1990). Antecedents of problem behaviours in children of depressed mothers. Development and psychopathology, 2(271-291).

Zahran, H. (1987). Dictionary of psychology. Cairo: Books world press.

Zaman, S. S., Banu, S., Habib, S., & Munir, S. Z. (1986). A comparitive study of intervention programmes for the mentally retarded in Bangaladesh. In J. M. Berg (Ed.), Sciences and services in mental retardation (pp. 403-414). New York: Methuen.

Zargar, A., Sofi, F., Laway, B., Masoodi, S., Shah, N., & Dar, F. (1996). Profile of nurological problems in diabetes mellitus. Annals of Saudi Medicine, 17, 20-25.

Zechmeister, S. (1990). Research methods in psychology: McGraw Hill.

Zigmond, A., & Snaith, R. (1983). The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandanavia, 67, 361-370.

Zuckerman, B., & Beardslee, W. (1987). Maternal depression: A concern for pediatricians. Pediatrics, 79, 110-117.

# APPENDIX (1)

## Interview schedule

### A-Family structure:

1- From your point of view, what is the family structure appropriate for the Saudi society, i.e. is the extended family " consisting of two generations or more" better, or the nuclear family "consisting of only the parents and the children"?

2- Do the grandparents play a positive role in raising this child and in your coping with the situation?

### B-Mother coping:

3- Do you turn to work or other activities to try and take your mind off things?

4- Do you try to concentrate your efforts on doing something about the situation you are in?

5- Do you believe that it has happened and try to live with it OR you denyand refuse to believe it saying to yourself "this isn't real"?

6- Have you ever use drugs such as tranquilizers or sleeping pills or any other drugs to make yourself feel better?

7- Are you dealing with it OR have you given up trying to deal with it?

8- Have you been expressing your negative feelings with someone or kept them to yourself?

9- In your view, is there any way to see it in a different light, to make it seem more positive?

10- Have you tried to plan for the future, and if so, which strategies are you going to use?

11- Have you made fun or jokes of the situation?

12- Do you criticise or blame yourself for things that happened?

13- In your opinion, what are the effects of religion or spiritual beliefs on your feelings?

14- In your view, what is the best way to follow in order to cope better in your situation?

**C- Social support:**

15- Do you receive support and get comfort and understanding from someone? If so, specify the people who are more supportive to you.

16- Have you tried to get help and advice from other people about what to do? If so, specify those people.

17- Do you feel that there are people who enjoy the same social activities you do, and who share your interests and concerns? If so, who are they?

18- Do you have a close personal relationship, or a strong emotional bond that provides you with a sense of emotional security and well-being with at least one other person? Specify that person.

**D-Stress:**

19- Can you tell me the things that your child does which bother you?

20- Do you feel that your child turned out to be more of problem than you had expected? If yes, Why?

21- How would you describe your relationship with your husband after having this child?

22- To what extent can you describe your social relationships after the birth of this child?

23- How can you appraise your relationship with this child compared with your other children or with the relationship between any other mother and her child?

**E-Mental Health:**

24- To what extent do you feel constantly haunted by anxiety, worry, or frightened feelings?

25- To what extent do you feel that you enjoy your life and the things you used to enjoy?

## APPENDIX (2)

## Demographic data sheet

Please answer all of the following question by using (    ) or writing the answer in the appropriate place.

**First: Information about the child:**

**Name (optional):** -----------------------------------------------------

**Age:** ---------------------------------------------------------------------

**Sex:** 1- Male --------- 2-Female----------

**Number of children in family** ----------------**Child birth order**: ----------------

**Does the child have other disabilities?** YES--------- NO----------

If YES specify the other disabilities-----------------------------------------------------

---------------------------------------------------------------------

**Type of school:**

1- Private---------- 2-Charity --------- 3-State ----

Other, please specify--------------------------------------------------------------

---------------------------------------------------------------

**Does anyone else in the family have a disability?**

YES----- NO-----

If yes, specify the person, his/her relationship to the child, and category of his/her disability---------------------------------------------------------

**Do you have anything you want to add?** -----------------------------------------

-------------------------------------------------------------------------------------------

-------------------------------------------------------------------------------------------

-------------------------------------------------------------------------------------------

**Second: Information about the mother and the family:**

**Mother's age:** -------------------------------------------------------------

**Marital status:**

Married------------- Divorced------------- Widowed -------------

**Do you have other children?** YES------ NO-------

If yes, how many--------------------------------------------------------------

**What is the highest level of education you have finished?**

1. Elementary----------------
2. Intermediate---------------
3. Secondary------------------
4. Bachelor--------------------
5. post-graduate------------

Other (specify)-------------------------------------------------------------

**Mother's occupation:** --------------------------------------------------

**Accommodation:**

a. Apartment--------------
b. Villa---------------------
c. House-------------------

Other (specify)----------------------------------------------------------------------------

---------------------------------------------------------------------

**Who lives with the family in the same house?** -----------------------------------

----------------------------------------------------------------------------------------------

------------------------------------------------------------

**How many times does the family visit Grandparents?**

a. Every day--------
b. Once a week--------
c. Twice a week --------
d. Once every two weeks -----------
e. Special occasions and religious festivals ------------

Other (specify)-------------------------------------------------------------

**How far away do the grandparents live?**

a. Grandparents live with the family in the same house---------------
b. Grandparents live in the same building, but other apartment------
c. Live in the same compound--------------
d. Live a few metres from your house (neighbour)---------
e. Live a few kilometres (in the same city)---------------
f. Live in other city-------------
Other (specify)--------------------------------------------------------------
-----------------------------------------------------------

**Who is responsible for making decisions in the family?**

a. The mother or the father-----------
b. The grandmother or the grandfather ------------
Other (specify)--------------------------------------------------------------
-----------------------------------------------------------

**The parent's relationship with their families?**

a. Excellent-------
b. Good--------
c. Bad ----------
Other (specify)-----------------------------------------------------------------
--------------------------------------------------------------------------------
--------------------------------------------------------------------------------

**Family income per year in Saudi Riyal:**

a. Less than 50.000 ---------
b. Between 50.000 to 80.000---------
c. Between 80.000 to 120.000 --------
d. More than 120.000-----------
Other (specify)--------------------------------------------------------------
-------------------------------------------------------

**Do you have any thing you would like to add?** --------------------------------
--------------------------------------------------------------------------------------
--------------------------

## APENDIX 3

## Self-evaluation

1. Name (optional) -------------------------------------------------------
2. Age -----------------------------------------------------------------------
3. Sex: 1. Male ----- 2. Female -----
4. Level of education (specify)-------------------------------------------------------
-------------------------------------------------------------------------

5. Please circle the appropriate answer below. Use the following scales to indicate your opinion:

1= very little
2= little
3= well
4= very well

| | | | | |
|---|---|---|---|---|
| 1. I understand English | 1 | 2 | 3 | 4 |
| 2. I read English | 1 | 2 | 3 | 4 |
| 3. I write English | 1 | 2 | 3 | 4 |
| 4. I speak English | 1 | 2 | 3 | 4 |

| | | | | |
|---|---|---|---|---|
| 1. I understand Arabic | 1 | 2 | 3 | 4 |
| 2. I read Arabic | 1 | 2 | 3 | 4 |
| 3. I write Arabic | 1 | 2 | 3 | 4 |
| 4. I speak Arabic | 1 | 2 | 3 | 4 |

# APPENDIX 4

## PSI-SF

This questionnaire contain 36 statement. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the **SA** if you strongly agree with the statement.
Circle the **A** if you agree with the statement.
Circle the **NS** if you not sure.
Circle the **D** if you disagree with the statement.
Circle the **SD** if you strongly disagree with the statement.

For example, if you some times enjoy going to the movie, you would circle A in response to the following statement:

I enjoy going to the movies SA A NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct answer. For example:

I enjoy going to the movies [✓ SA] A ~~NS~~ D SD

| SA= Strongly Agree A=Agree NS=Not Sure D= Disagree SD=Strongly Disagree | | | | | |
|---|---|---|---|---|---|
| 1. I often have the feeling that I cannot handle things very well | SA | A | NS | D | SD |
| 2.I find myself giving up more of my life to meet my children's needs than I ever expected | SA | A | NS | D | SD |
| 3. I feel trapped by my responsibilities as a parent | SA | A | NS | D | SD |
| 4. Since having this child, I have been unable to do new and different things | SA | A | NS | D | SD |
| 5. Since having this child, I feel that I am almost never able to do things that I like to do | SA | A | NS | D | SD |
| 6. I am unhappy with the last purchase of clothing I made for myself | SA | A | NS | D | SD |
| 7. There are quite few things that bother me about my life | SA | A | NS | D | SD |
| 8. Having a child has caused more problems than I expected in my relationship with my spouse | SA | A | NS | D | SD |
| 9. I feel alone without friends | SA | A | NS | D | SD |
| 10. When I go to a party, I usually expect not to enjoy myself | SA | A | NS | D | SD |
| 11. I am not as interested in people as I used to be | SA | A | NS | D | SD |
| 12. I don't enjoy things as I used to | SA | A | NS | D | SD |
| 13. My child rarely does things for me that make me feel good | SA | A | NS | D | SD |
| 14. Most times I feel that my child does not like me and does not want to be close to me | SA | A | NS | D | SD |
| 15. My child smiles at me much less than I expected | SA | A | NS | D | SD |
| 16. When I do things for my child, I get the feeling that my efforts are not appreciated very much | SA | A | NS | D | SD |
| 17. When playing, my child doesn't often giggle or laugh | SA | A | NS | D | SD |
| 18. My child doesn't seem to learn as quickly as most children | SA | A | NS | D | SD |
| 19. My child doesn't seem to smile as much as most children | SA | A | NS | D | SD |
| 20. My child is not able to do as much as I expected | SA | A | NS | D | SD |
| 21. It takes a long time and it is very hard for my child to get used to new things | SA | A | NS | D | SD |
| For next statement choose your response from the choice "1" to "5" below.<br>22. I feel that I am: 1. not very good at being parent<br>2. a person who has some trouble being a parent<br>3. an average parent<br>4. a better than average parent<br>5. a very good parent | 1 | 2 | 3 | 4 | 5 |
| 23. I expected to have closer and warmer feelings for my child than I do, and this bothers me | SA | A | NS | D | SD |
| 24. Sometimes my child does things that bother me just to be mean | SA | A | NS | D | SD |
| 25. My child seems to cry or fuss more often than most children | SA | A | NS | D | SD |
| 26. My child generally wakes up in a bad mood | SA | A | NS | D | SD |
| 27. I feel that my child is very moody and easily upset | SA | A | NS | D | SD |
| 28. My child does a few things which bother me a great deal | SA | A | NS | D | SD |
| 29. My child reacts very strongly when something happens that my child doesn't like | SA | A | NS | D | SD |
| 30. My child gets upset easily over the smallest thing | SA | A | NS | D | SD |
| 31. My child's sleeping or eating schedule was much harder to establish than I expected | SA | A | NS | D | SD |
| For the next statement, choose your response from the choice "1" to "5" below.<br>32. I have found that getting my child to do something or stop doing something is:<br>1. Much harder than I expected<br>2. somewhat harder than I expected<br>3. about as hard as I expected<br>4. much easier than I expected | 1 | 2 | 3 | 4 | 5 |
| For the next statement, choose your response from the choice "10+" to "1-3"<br>33. Think carefully and count the number of things, which your child does, that bothers you. For example: dawdles, refuse to listen, overactive, cries, interrupts,fights, whines, etc. | 10+ | 8-9 | 6-7 | 4-5 | 1-3 |
| 34. There are some things my child does that really bother me a lot | | A | NS | D | SD |
| 35. My child turned out to be more of problem than I had expected | | A | NS | D | SD |
| 36. My child makes more demands on me than most children | | A | NS | D | SD |

# APPENDIX 5

## Brief COPE

These items deal with the ways you've been coping with the stress in your life since you have faced this situation (think about a specific stressful situation that bother you). There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I am interested in how you've tried to deal with it. Each item says something about particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not, just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

**1=** I haven't been doing this at all
**2=** I've been doing this a little bit
**3=** I've been doing this a medium amount
**4=** I've been doing this a lot

| | | | | | |
|---|---|---|---|---|---|
| 1 | I've been turning to work or other activities to take my mind of things. | 1 | 2 | 3 | 4 |
| 2 | I've been concentrating my efforts on doing something about the situation I'm in. | 1 | 2 | 3 | 4 |
| 3 | I've been saying to myself "this isn't real". | 1 | 2 | 3 | 4 |
| 4 | I've been using drugs such as tranquilizers to make myself feel better. | 1 | 2 | 3 | 4 |
| 5 | I've been getting emotional support from others. | 1 | 2 | 3 | 4 |
| 6 | I've been giving up trying to deal with it. | 1 | 2 | 3 | 4 |
| 7 | I've been taking action to try to make the situation better. | 1 | 2 | 3 | 4 |
| 8 | I've been refusing to believe that it has happened. | 1 | 2 | 3 | 4 |
| 9 | I've been saying things to let my unpleasant feelings escape. | 1 | 2 | 3 | 4 |
| 10 | I've been getting help and advice from other people. | 1 | 2 | 3 | 4 |
| 11 | I've been using drugs or tranquilizers to help me get through it. | 1 | 2 | 3 | 4 |
| 12 | I've been trying to see it in different light, to make it seem more positive. | 1 | 2 | 3 | 4 |
| 13 | I've been criticizing myself. | 1 | 2 | 3 | 4 |
| 14 | I've been trying to come up with a strategy about what to do. | 1 | 2 | 3 | 4 |
| 15 | I've been getting comfort and understanding from someone. | 1 | 2 | 3 | 4 |
| 16 | I've been giving up the attempt to cope. | 1 | 2 | 3 | 4 |
| 17 | I've been looking for something good in what is happening. | 1 | 2 | 3 | 4 |
| 18 | I've been making jokes about it. | 1 | 2 | 3 | 4 |
| 19 | I've been doing something to think about it less, such as going watching TV, reading, daydreaming, sleeping, or shopping. | 1 | 2 | 3 | 4 |
| 20 | I've been accepting the reality of the fact that it has happened. | 1 | 2 | 3 | 4 |
| 21 | I've been expressing my negative feelings. | 1 | 2 | 3 | 4 |
| 22 | I've been trying to find comfort in my religion or spiritual beliefs. | 1 | 2 | 3 | 4 |
| 23 | I've been trying to get advice or help from other people about what to do. | 1 | 2 | 3 | 4 |
| 24 | I've been learning to live with it. | 1 | 2 | 3 | 4 |
| 25 | I've been thinking hard about what steps to take. | 1 | 2 | 3 | 4 |
| 26 | I've been blaming myself for things that happened. | 1 | 2 | 3 | 4 |
| 27 | I've been prying or mediating. | 1 | 2 | 3 | 4 |
| 28 | I've been making fun of the situation. | 1 | 2 | 3 | 4 |

## APPENDIX 6

## Social Provision Scale

Instructions: In answering the following questions, think about your current relationship with friends, family members, co-workers, community members, and so on. Please indicate to what extent each statement describes your current relationships with other people. Use the following scale to indicate your opinion.

| **STRONGLY DISAGREE** | **DISAGREE** | **AGREE** | **STRONGLY AGREE** |
|---|---|---|---|
| **1** | **2** | **3** | **4** |

So, for example, if you feel a statement is very true of your current relationship, you would respond with a 1 (strongly disagree).

| | | | | |
|---|---|---|---|---|
| 1. There are people I can depend on help me if I really need it. | 1 | 2 | 3 | 4 |
| 2. I feel that I do not have close personal relationships with other people. | 1 | 2 | 3 | 4 |
| 3. There is no one I can turn to for guidance in time for stress. | 1 | 2 | 3 | 4 |
| 4. There are people who depend on me for help. | 1 | 2 | 3 | 4 |
| 5.There are people who enjoy the same social activities I do. | 1 | 2 | 3 | 4 |
| 6. Other people do not view me as competent. | 1 | 2 | 3 | 4 |
| 7. I feel personally responsible for the well-being of another person. | 1 | 2 | 3 | 4 |
| 8. I feel part of a group of people who share my attitudes and beliefs. | 1 | 2 | 3 | 4 |
| 9. I do not think other people respect my skills and abilities. | 1 | 2 | 3 | 4 |
| 10. If someone went wrong, no one would come to my assistance. | 1 | 2 | 3 | 4 |
| 11. I have close relationships that provide me with a sense of emotional security and well-being. | 1 | 2 | 3 | 4 |
| 12. There is someone I could talk to about important decisions in my life. | 1 | 2 | 3 | 4 |
| 13. I have relationship where my competence and skill are recognized. | 1 | 2 | 3 | 4 |
| 14. There is no one who shares my interests and concerns. | 1 | 2 | 3 | 4 |
| 15. There is no one who really relies on me for their well-being. | 1 | 2 | 3 | 4 |
| 16. There is a trustworthy person I could turn to for advice if I were having problems. | 1 | 2 | 3 | 4 |
| 17. I feel a strong emotional bond with at least one other person. | 1 | 2 | 3 | 4 |
| 18. There is no one I can depend on for aid if I really need it. | 1 | 2 | 3 | 4 |
| 19. There is no one I feel comfortable talking about problems with. | 1 | 2 | 3 | 4 |
| 20. There are people who admire my talents and abilities. | 1 | 2 | 3 | 4 |
| 21. I lack a feeling of intimacy with another person. | 1 | 2 | 3 | 4 |
| 22. There is no one who likes to do the things I do. | 1 | 2 | 3 | 4 |
| 23. There are people who I can count on in an emergency. | 1 | 2 | 3 | 4 |
| 24. No one needs me to care for them. | 1 | 2 | 3 | 4 |

# APPENDIX 7
## Family Support Scale

Listed below are sources of support that are often helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (not available) response. You can add any others who are not mentioned below.

NA= Not available
1= Not helpful at all
2= Sometimes helpful
3= Generally helpful
4= Very helpful
5= Extremely helpful

| | | | | | | |
|---|---|---|---|---|---|---|
| 1. My parents | NA | 1 | 2 | 3 | 4 | 5 |
| 2. My spouse's parents | NA | 1 | 2 | 3 | 4 | 5 |
| 3. My relatives/Kin | NA | 1 | 2 | 3 | 4 | 5 |
| 4. My spouse's relatives/kin | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Spouse | NA | 1 | 2 | 3 | 4 | 5 |
| 6. My friends | NA | 1 | 2 | 3 | 4 | 5 |
| 7. My spouse's friends | NA | 1 | 2 | 3 | 4 | 5 |
| 8. My own children | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Other parents | NA | 1 | 2 | 3 | 4 | 5 |
| 10. Co-worker | NA | 1 | 2 | 3 | 4 | 5 |
| 11. Parent groups | NA | 1 | 2 | 3 | 4 | 5 |
| 12. Social groups/clubs | NA | 1 | 2 | 3 | 4 | 5 |
| 13. Place of worship/ religious organization | NA | 1 | 2 | 3 | 4 | 5 |
| 14. My family or child's doctor | NA | 1 | 2 | 3 | 4 | 5 |
| 15. Professional helpers (social workers, therapists, teachers, etc) | NA | 1 | 2 | 3 | 4 | 5 |
| 16. Professional agencies (public health, social services, mental health, etc) | NA | 1 | 2 | 3 | 4 | 5 |
| 17. School/day-care centre | NA | 1 | 2 | 3 | 4 | 5 |
| 18. Early intervention programme | NA | 1 | 2 | 3 | 4 | 5 |
| 19. | NA | 1 | 2 | 3 | 4 | 5 |
| 20. | NA | 1 | 2 | 3 | 4 | 5 |

# APPENDIX 8

## HADS

Read each item and please circle the answer, which comes closest to how you have been feeling, on the average, in the past week. Don't take too long over your answers; your immediate reaction to each item will probably be more accurate than a long thought out response.

| **1- I feel tense or "wound up":** |
|---|
| a. Most of the time |
| b. A lot of the time |
| c. From time to time |
| d. Not at all |

| **2- I still enjoy the things I used to enjoy:** |
|---|
| a. Definitely as much |
| b. Not quite as much |
| c. Only a little |
| d. Hardly at all |

| **3- I get a sort of frightened feeling as if something awful is about to happen:** |
|---|
| a. Very definitely and quite badly |
| b. Yes, but not too badly |
| c. A little, but it doesn't worry me |
| d. Not at all |

| **4- I can laugh and see the funny side of things:** |
|---|
| a. As much as always could |
| b. Not quite as much now |
| c. Definitely not so much now |
| d. Not at all |

| **5- Worrying thoughts go through my mind:** |
|---|
| a. A great deal of time |
| b. A lot of time |
| c. From time to time but not too often |
| d. Only occasionally |

| **6- I feel cheerful:** |
|---|
| a. Not at all |
| b. Not often |
| c. Sometimes |
| d. Most of time |

| **7- I can sit at ease and feel relaxed:** |
|---|
| a. Definitely |
| b. Usually |
| c. Not often |
| d. Not at all |

| **8- I feel as if I am slowed down:** |
|---|
| a. Nearly all the time |
| b. Very often |
| c. Sometimes |
| d. Not at all |

| **9- I get sort of frightened feeling like “butterflies” in the stomach:** |
|---|
| a. Not at all |
| b. Occasionally |
| c. Quite often |
| d. Very often |

| **10- I have lost interest in my appearance:** |
|---|
| a. Definitely |
| b. I don’t take as much care as I should |
| c. I may not take quite as much care |
| d. I take just as much care as ever |

| **11- I feel restless as if I have to be on the move:** |
|---|
| a. Very much indeed |
| b. Quite a lot |
| c. Not very much |
| d. Not at all |

| **12- I look forward with enjoyment to things:** |
|---|
| a. As much as I ever did |
| b. Rather less than I used to |
| c. Definitely less than I used to |
| d. Hardly at all |

| **13- I get sudden feelings of panic:** |
|---|
| a. Very often indeed |
| b. Quite often |
| c. Not very often |
| d. Not at all |

| **14- I can enjoy a good book or radio or TV program:** |
|---|
| a. Often |
| b. Sometimes |
| c. Not often |
| d. Very seldom |

# APPENDIX 9
# Strength and Difficulties Questionnaire (SDQ)

For each item, please mark the box for Not True, Somewhat True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behavior over the last six months.

| | Not True | Somewhat True | Certainly True |
|---|---|---|---|
| Considerate of other people's feelings | | | |
| Restless, overactive, cannot stay still for long | | | |
| Often complains of headaches, stomach-aches of sickness | | | |
| Shares readily with other children (treats, toys, pencils etc.) | | | |
| Often has temper tantrums or hot tempers | | | |
| Rather solitary, tends to play alone | | | |
| Generally obedient, usually does what adults request | | | |
| Many worries, often seems worried | | | |
| Helpful if someone is hurt, upset or feeling ill | | | |
| Constantly fidgeting or squirming | | | |
| Has at least one good friend | | | |
| Often fights with other children, or bullies them | | | |
| Often unhappy, down-hearted or tearful | | | |
| Generally liked by other children | | | |
| Easily distracted, concentration wanders | | | |
| Nervous or clingy in new situation, easily loses confidence | | | |
| Kind to younger children | | | |
| Often lies or cheat | | | |
| Picked on or bullied by other children | | | |
| Often volunteers to help others (parents, teachers, other children) | | | |
| Thinks things out before acting | | | |
| Steals from home, school or else where | | | |
| Gets on better with adults than with other children | | | |
| Many fears, easily scared | | | |
| Sees tasks through to the end, good attention span | | | |

# APPENDIX 10
## Summary Demographic Data for Saudi Arabia

Demographic Indicators: 2000 and 2025

| | 2000 | 2025 |
|---|---|---|
| Births per 1,000 population.................... | 30 | 22 |
| Deaths per 1,000 population.................... | 3 | 3 |
| Rate of natural increase (percent)............ | 2.7 | 1.9 |
| Annual rate of growth (percent)............... | 2.9 | 1.3 |
| Life expectancy at birth (years).............. | 74.3 | 79.1 |
| Infant deaths per 1,000 live births........... | 16 | 7 |
| Total fertility rate (per woman).............. | 4.4 | 2.9 |

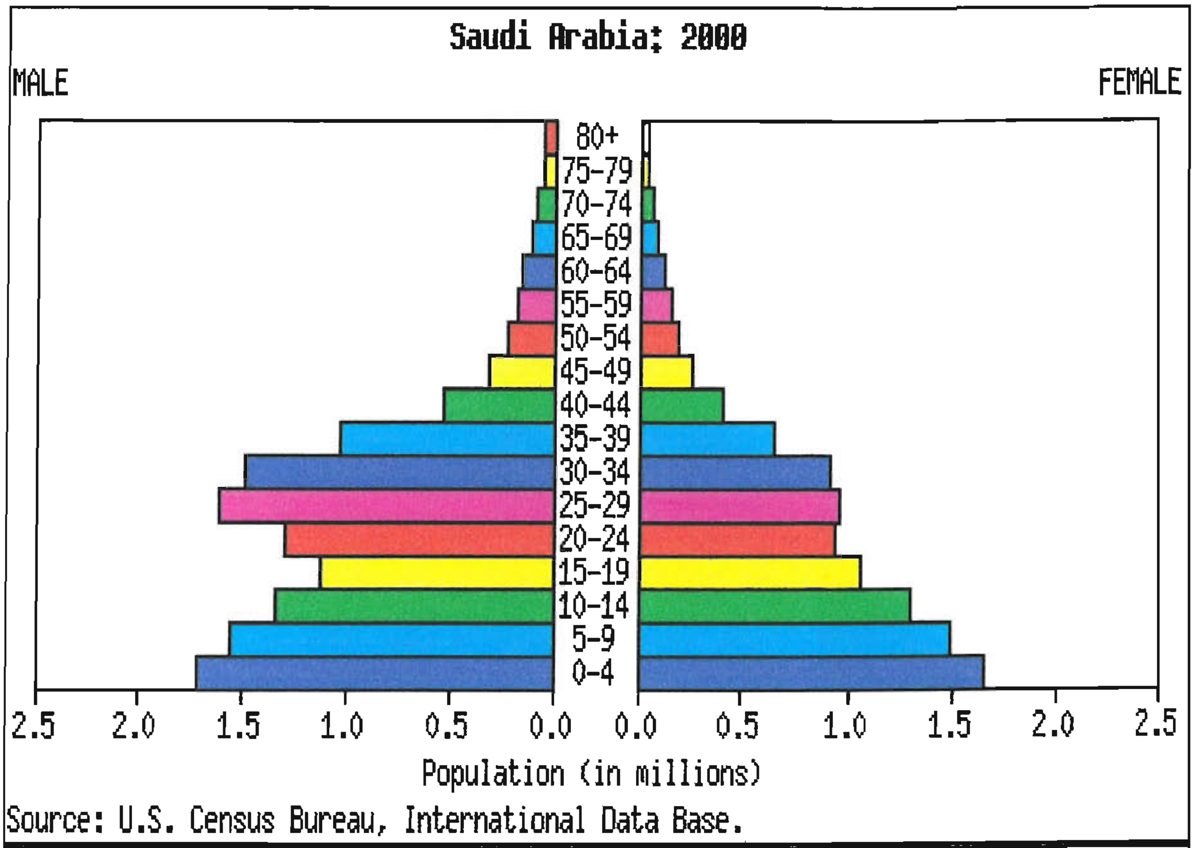
Midyear Population Estimates and Average Annual Period Growth Rates: 1950 to 2050
(Population in thousands, rate in percent)

| Year | Population | Year | Population | Period | Growth Rate |
|---|---|---|---|---|---|
| 1950 | 3,860 | 1995 | 19,967 | 1950-1960 | 2.0 |
| 1960 | 4,718 | 1996 | 20,626 | 1960-1970 | 2.6 |
| 1970 | 6,109 | 1997 | 21,230 | 1970-1980 | 4.9 |
| 1980 | 9,999 | 1998 | 21,843 | 1980-1990 | 4.7 |
| 1990 | 16,061 | 1999 | 22,484 | 1990-2000 | 3.7 |
| 2000 | 23,153 | 2010 | 29,222 | 2000-2010 | 2.3 |
| 2001 | 23,833 | 2020 | 33,577 | 2010-2020 | 1.4 |
| 2002 | 24,502 | 2030 | 38,142 | 2020-2030 | 1.3 |
| 2003 | 25,157 | 2040 | 43,938 | 2030-2040 | 1.4 |
| 2004 | 25,796 | 2050 | 49,707 | 2040-2050 | 1.2 |

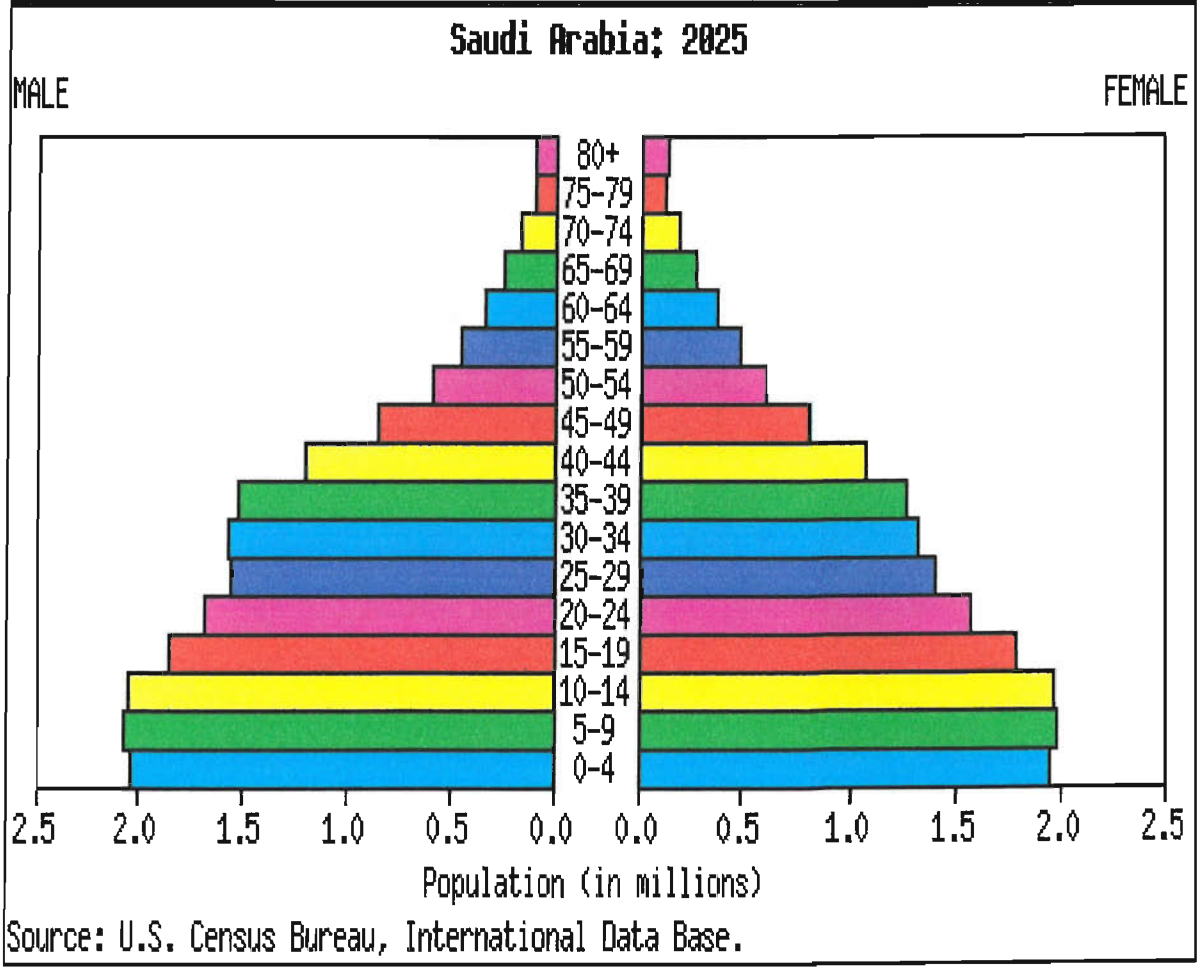
Midyear Population, by Age and Sex: 2000 and 2025
(Population in thousands)

| | 2000 | | | 2025 | | |
|---|---|---|---|---|---|---|
| AGE | TOTAL | MALE | FEMALE | TOTAL | MALE | FEMALE |
| TOTAL | 23,153 | 12,865 | 10,288 | 35,669 | 18,377 | 17,292 |
| 0-4 | 3,361 | 1,716 | 1,645 | 3,978 | 2,034 | 1,944 |
| 5-9 | 3,050 | 1,555 | 1,495 | 4,058 | 2,073 | 1,985 |
| 10-14 | 2,631 | 1,339 | 1,292 | 4,014 | 2,049 | 1,965 |
| 15-19 | 2,185 | 1,128 | 1,058 | 3,641 | 1,860 | 1,781 |
| 20-24 | 2,220 | 1,294 | 927 | 3,261 | 1,688 | 1,573 |
| 25-29 | 2,570 | 1,615 | 956 | 2,956 | 1,561 | 1,395 |
| 30-34 | 2,399 | 1,486 | 913 | 2,887 | 1,566 | 1,321 |
| 35-39 | 1,685 | 1,033 | 652 | 2,783 | 1,522 | 1,261 |
| 40-44 | 934 | 534 | 400 | 2,270 | 1,202 | 1,068 |
| 45-49 | 576 | 317 | 259 | 1,663 | 845 | 818 |
| 50-54 | 404 | 220 | 183 | 1,202 | 588 | 615 |
| 55-59 | 329 | 180 | 149 | 935 | 451 | 484 |
| 60-64 | 271 | 149 | 123 | 705 | 335 | 369 |
| 65-69 | 204 | 114 | 91 | 518 | 245 | 274 |
| 70-74 | 148 | 85 | 63 | 351 | 161 | 190 |
| 75-79 | 93 | 53 | 41 | 215 | 95 | 120 |
| 80+ | 91 | 48 | 43 | 231 | 102 | 130 |

Source: U.S. Census Bureau, International Data Base, March 2004 version.

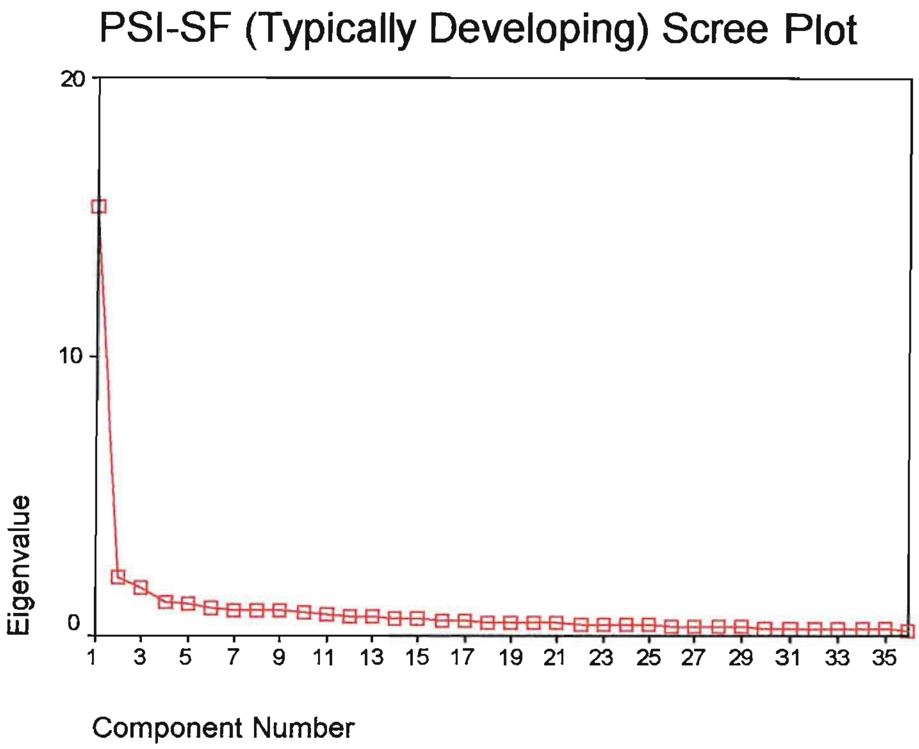


Source: U.S. Census Bureau, International Data Base.



Source: U.S. Census Bureau, International Data Base.

# APPENDIX 11


PSI-SF (Typically Developing) Scree Plot
Eigenvalue
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10
0
Component Number
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5
7
9
11
13
15
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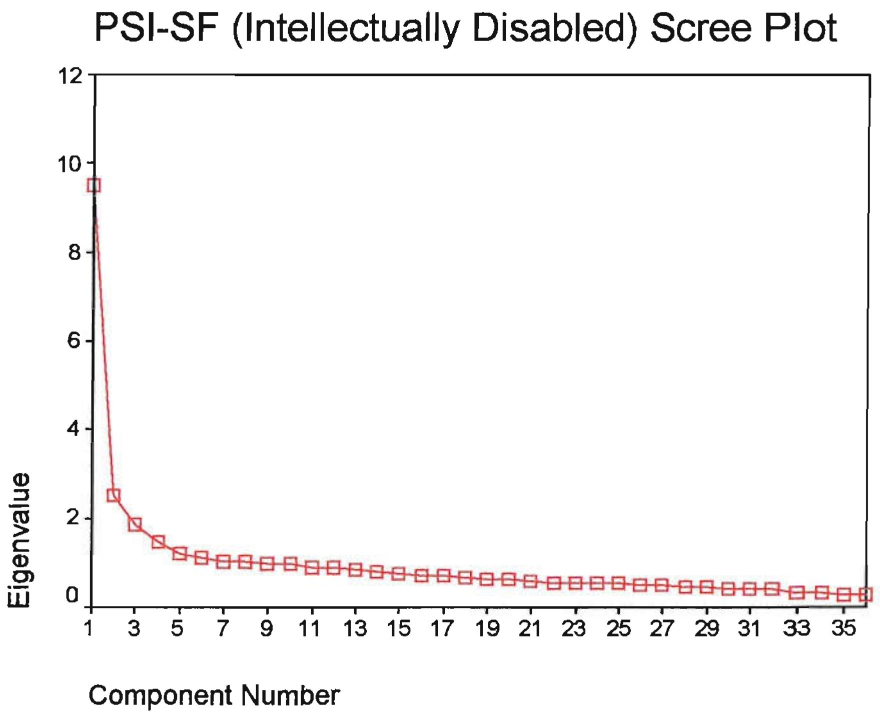
19
21
23
25
27
29
31
33
35


PSI-SF (Intellectually Disabled) Scree Plot
Eigenvalue
12
10
8
6
4
2
0
Component Number
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7
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19
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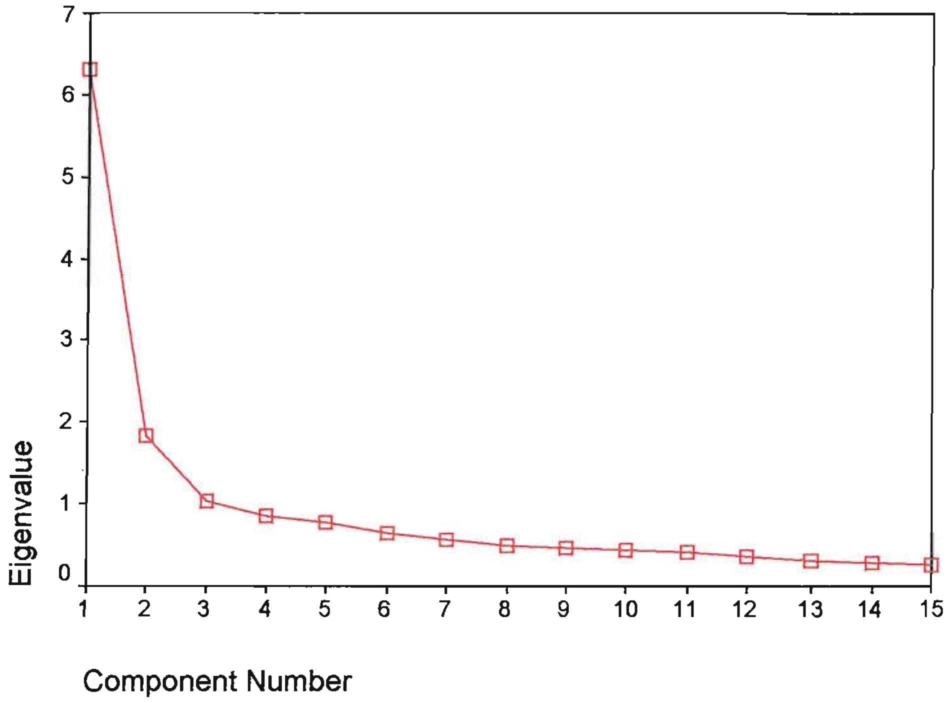
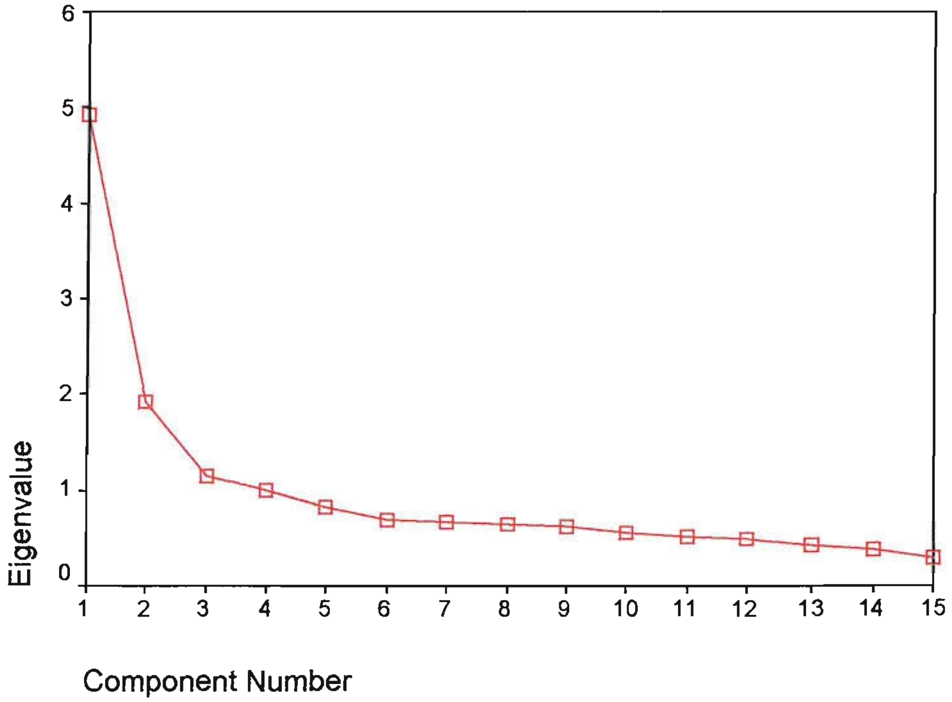
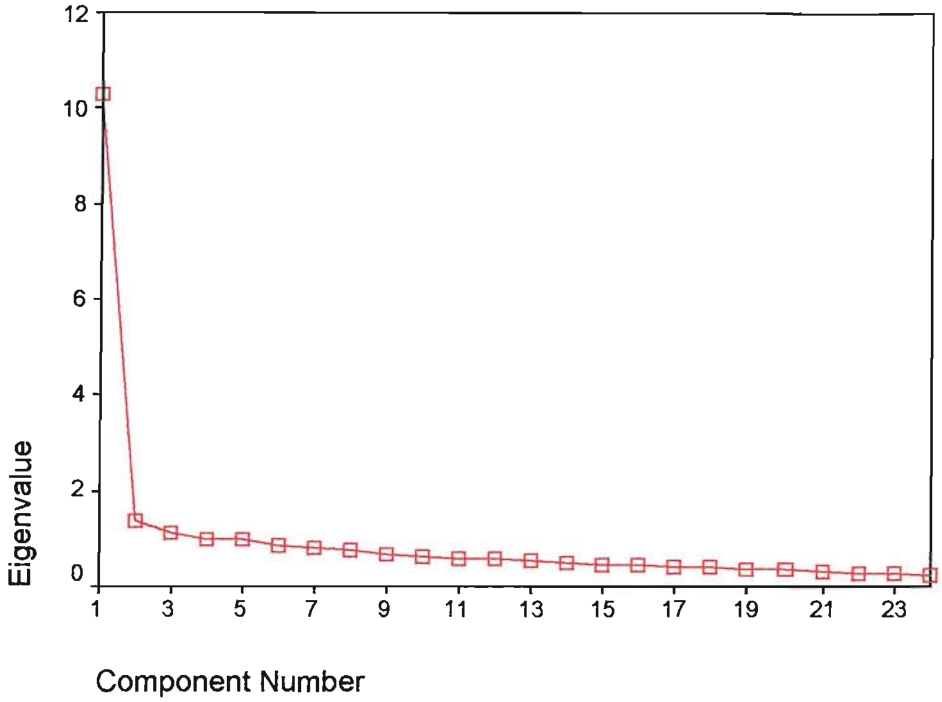
23
25
27
29
31
33
35



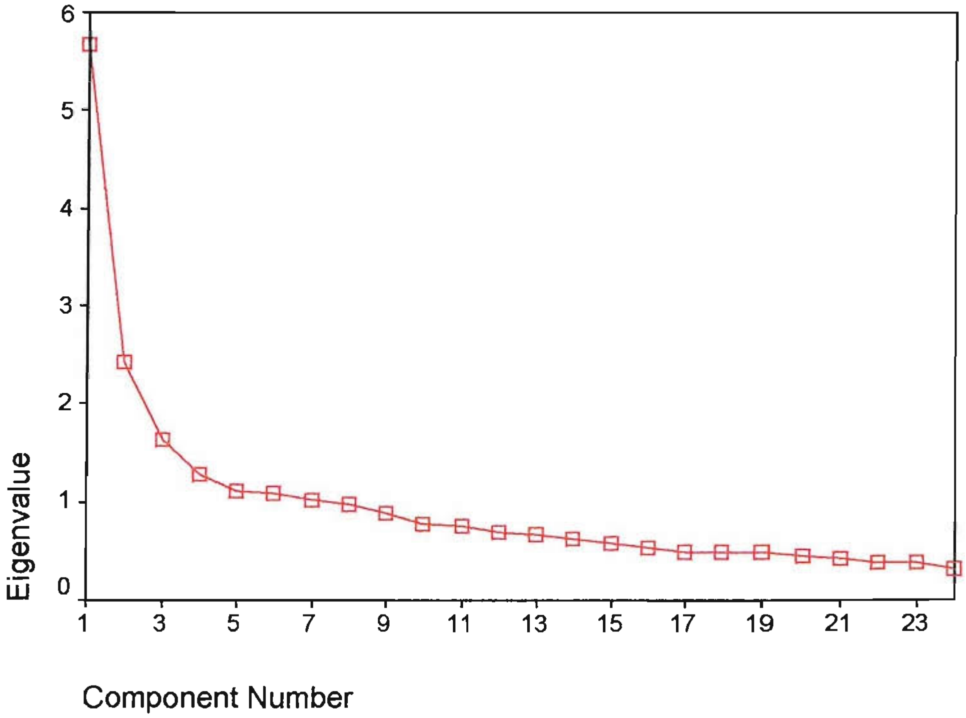
Brief COPE (Typically Developing) Scree Plot



Brief COPE (Intellectually Disabled) Scree Plot

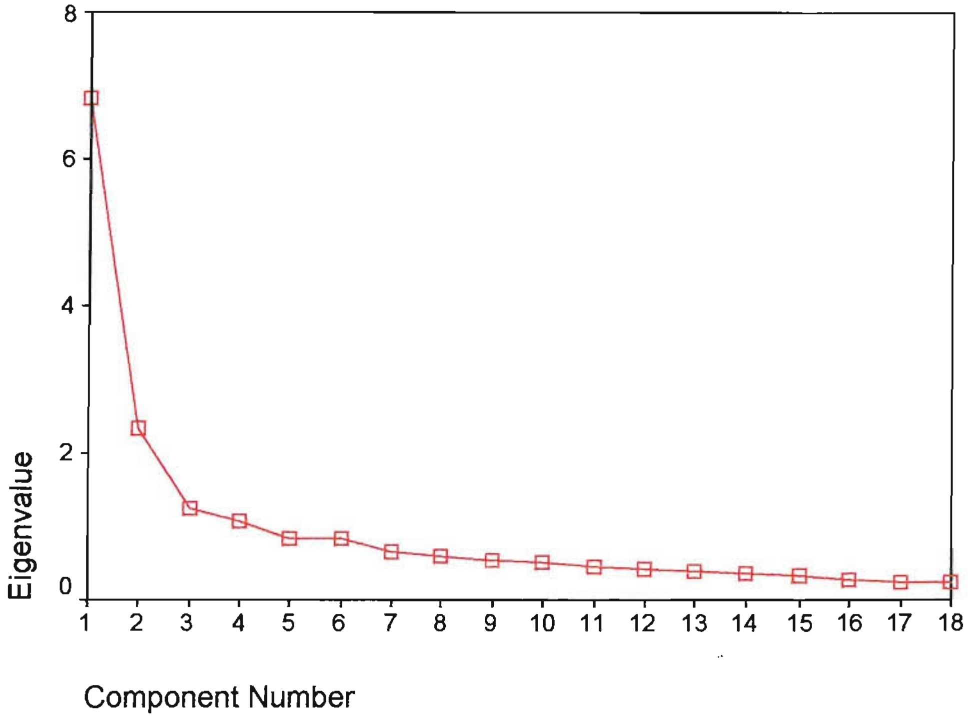


SPS (Typically Developing) Scree Plot

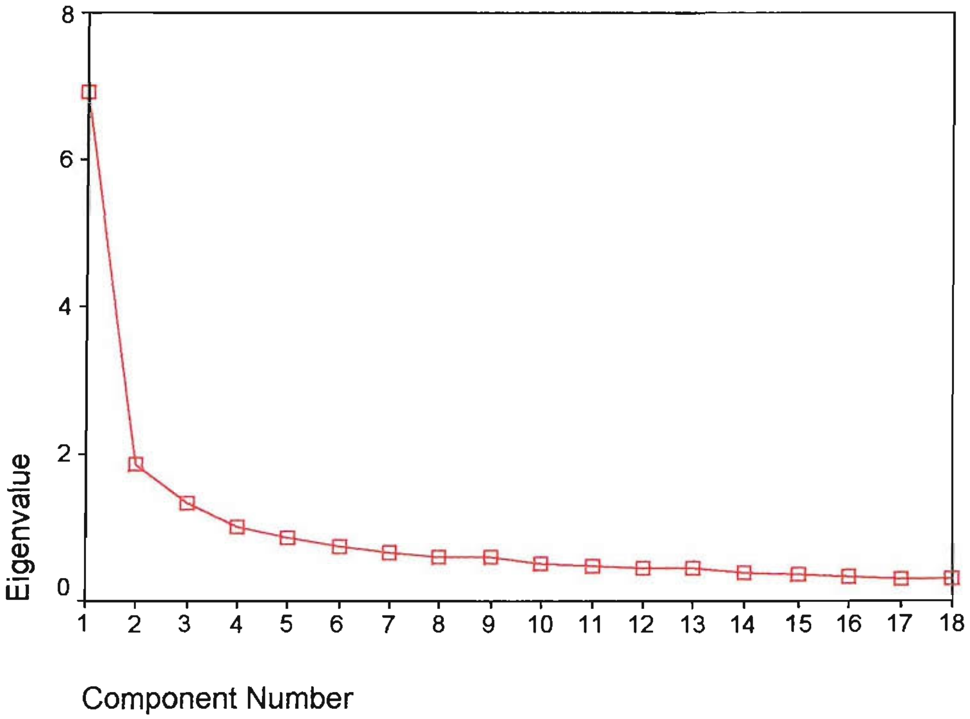


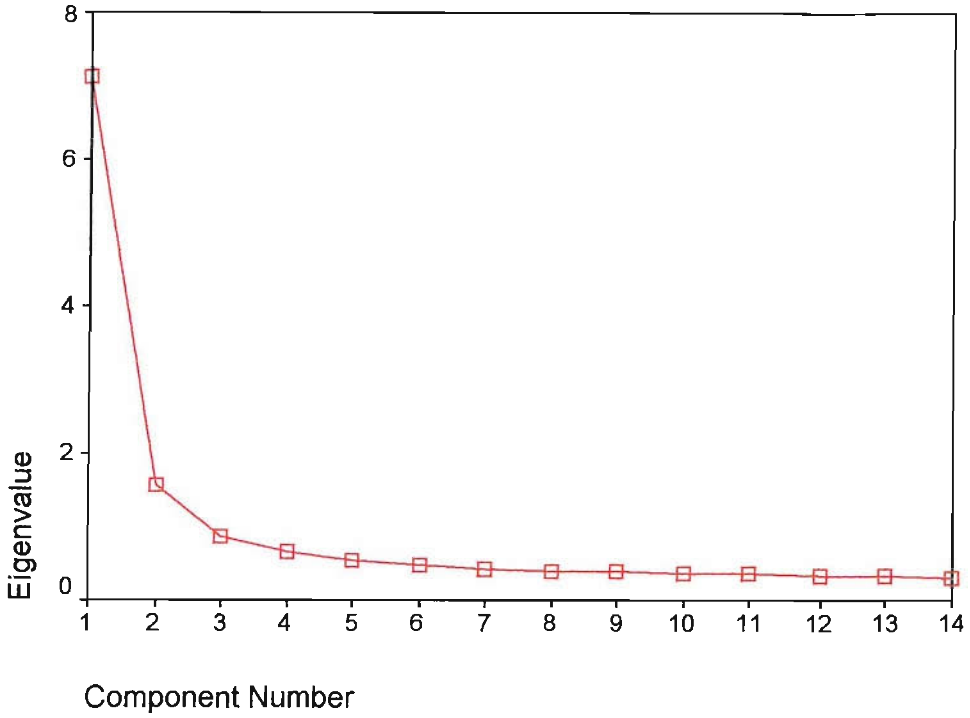
SPS (Intellectually Disabled) Scree Plot

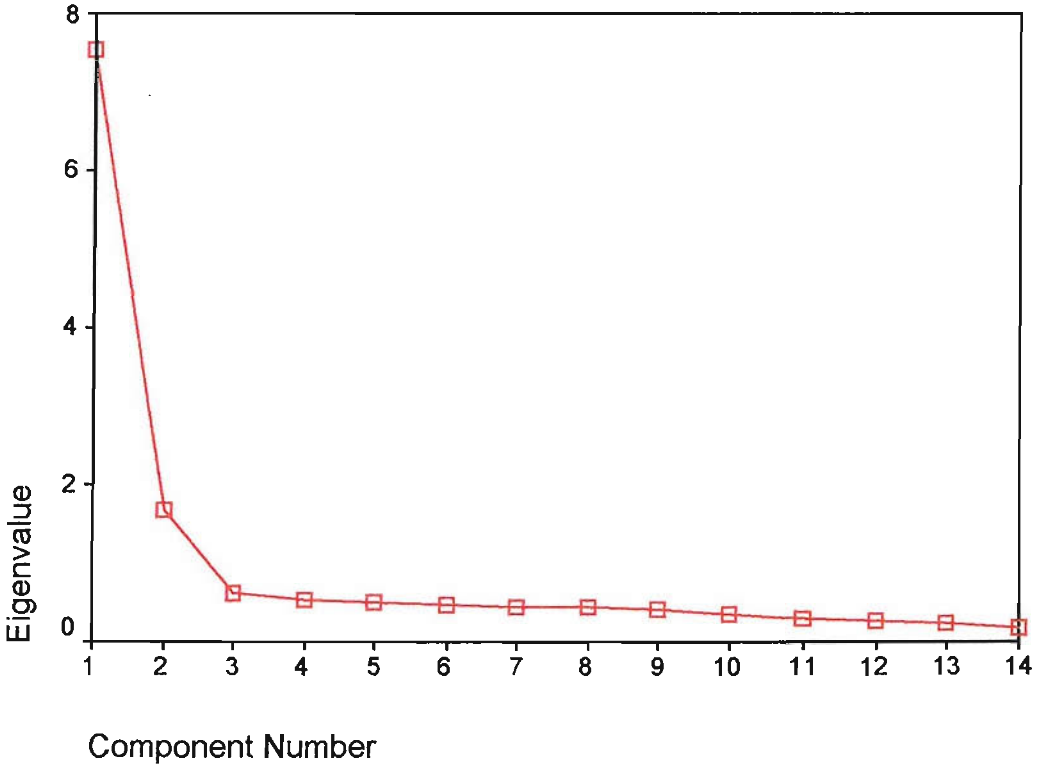
FSS (Typically Developing) Scree Plot

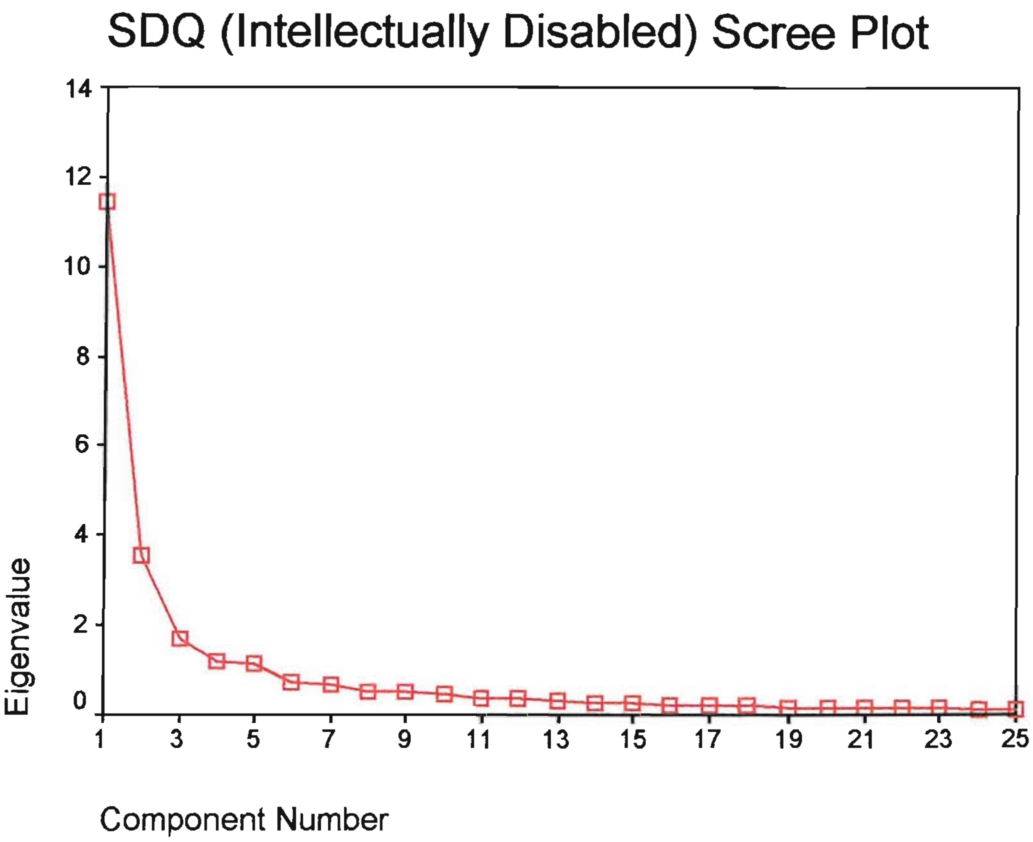


FSS (Intellectually Disabled) Scree Plot




HADS (Typically Developing) Scree Plot


HADS (Intellectually Disabled) Scree Plot


SDQ (Intellectually Disabled) Scree Plot
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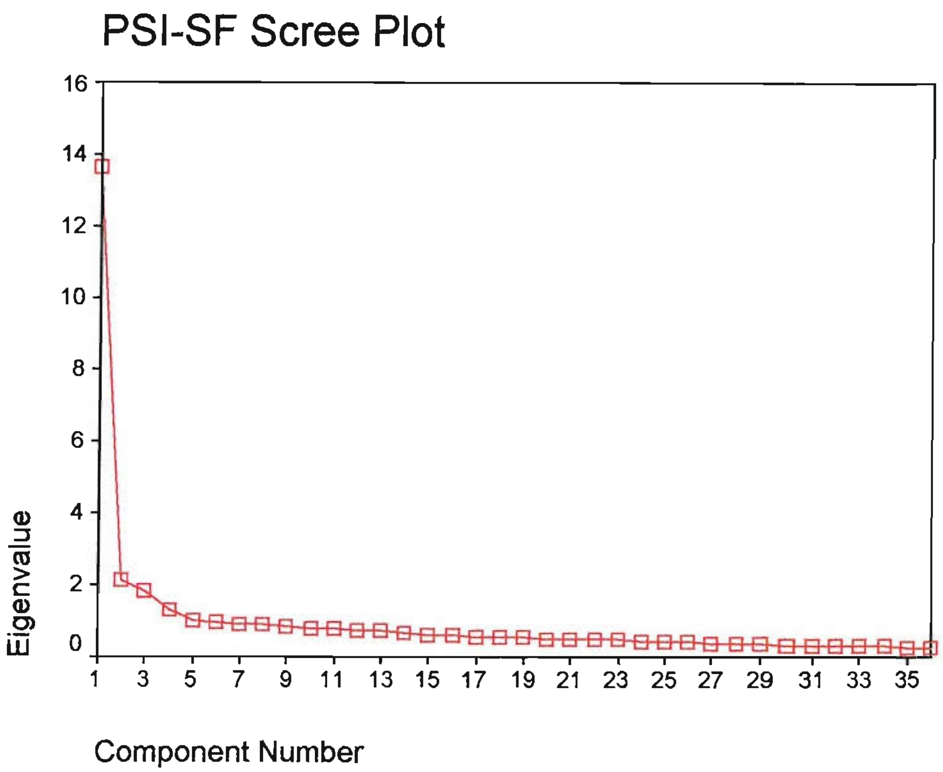
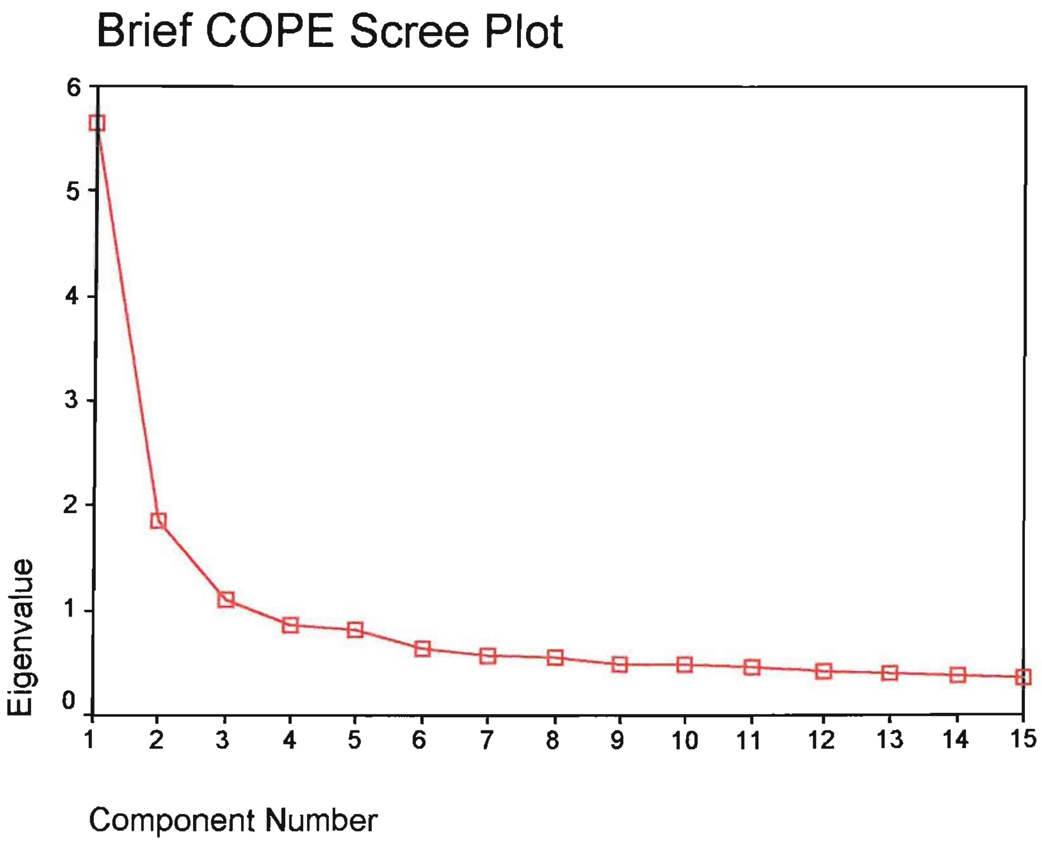
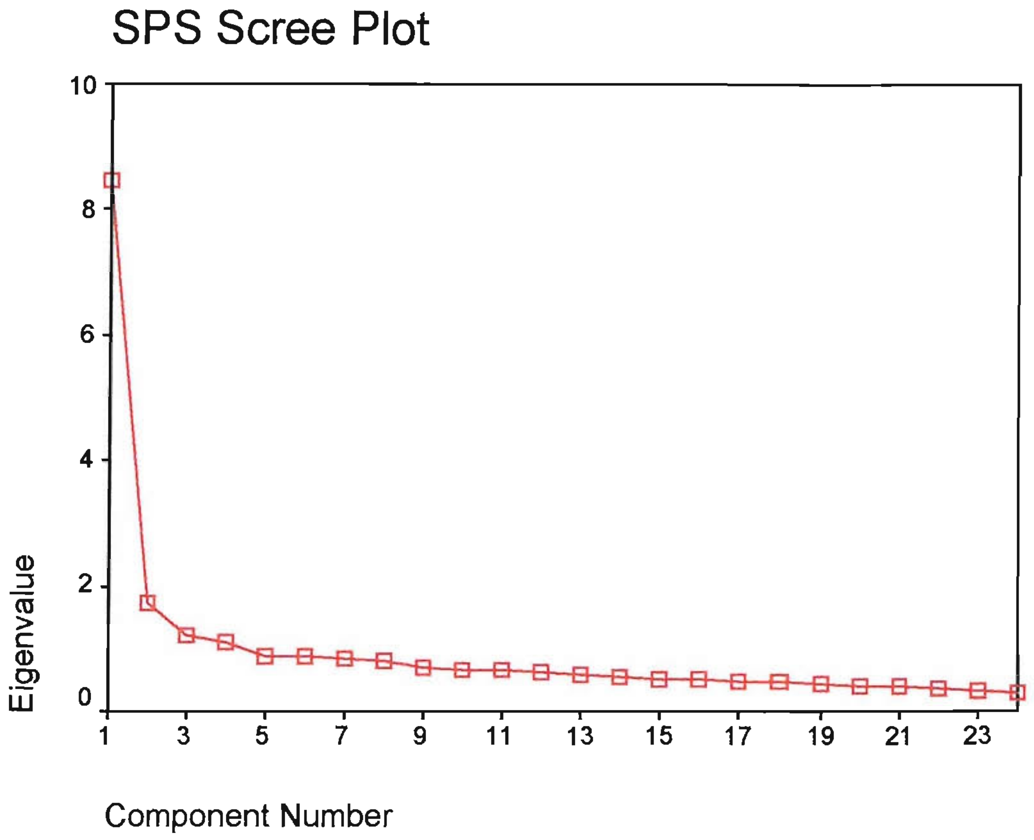
12
10
8
6
4
2
0
Eigenvalue
1
3
5
7
9
11
13
15
17
19
21
23
25
Component Number

# APPENDIX 12

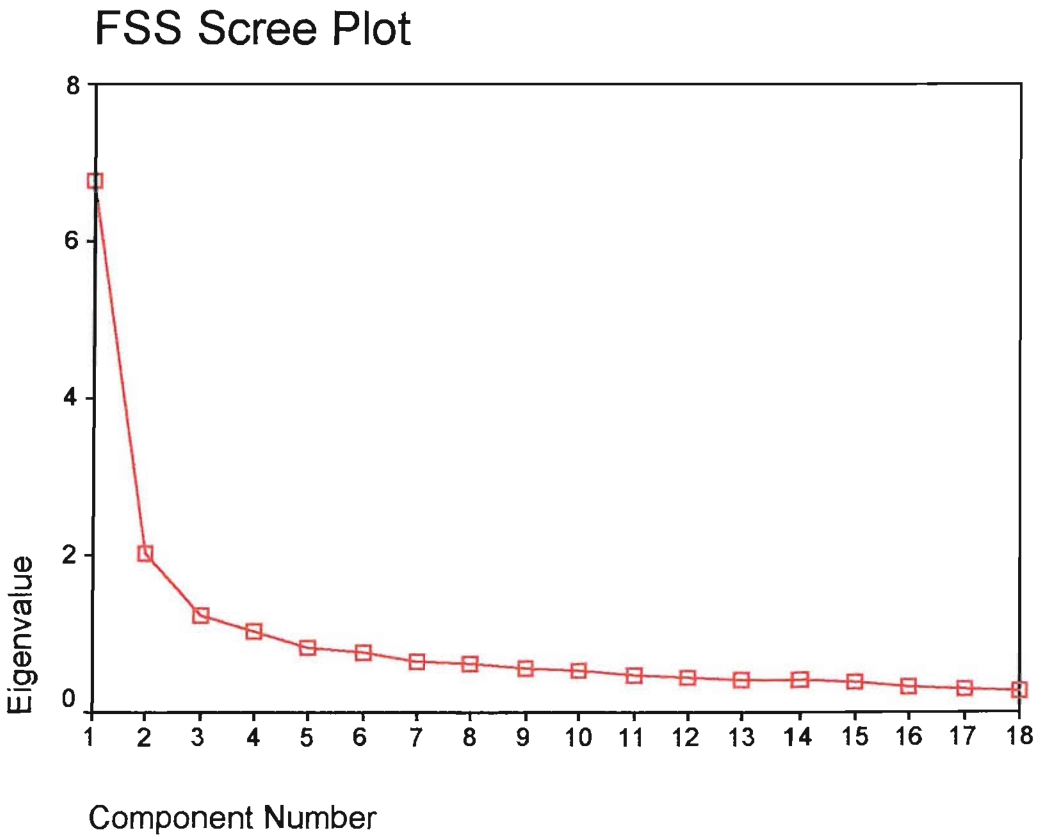
Scree plot of all participants (typically developing and intellectually disabled)



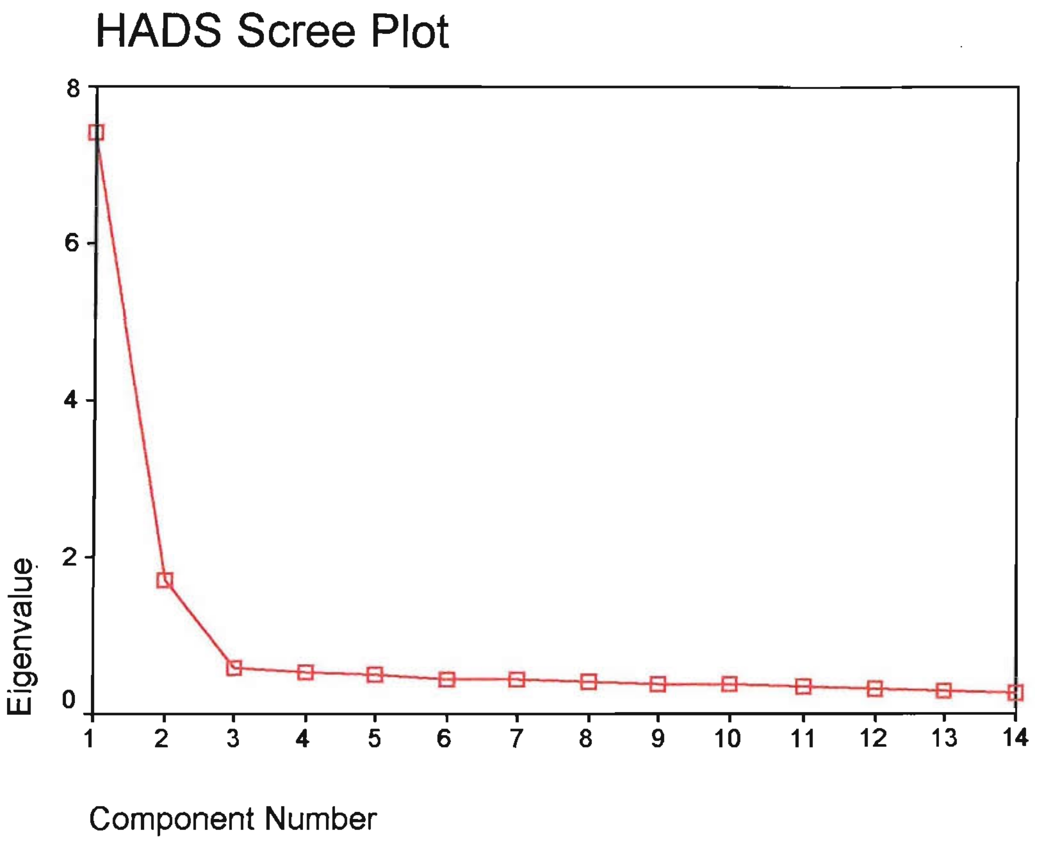




SPS Scree Plot



FSS Scree Plot


HADS Scree Plot
Eigenvalue
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3
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7
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11
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13
14
Component Number