# FIT Science for Improving Family Functioning and Parental Stress

# Shivani Sharma

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#### **Preface**

Autism is a lifelong, neurodevelopmental disability, which before starting my undergraduate degree I had only heard about in the media. As an undergraduate I began working with children with autism in schools, and on various Early Intensive Behavioural Programmes. It was then I came to learn about the challenges parents face when raising a child on the autistic spectrum. I also began to look into the research literature and it was clear that there are large variations in how parents adapt to raising a child with autism. Through volunteering on a number of projects where I was able to interact with parents, I also found that differences in coping abilities did not vary, at least consistency, as a function of parent education, or social economic status. This motivated me to explore the variables that make some people more resilient in the face of family stressors than others. I was also interested in how this knowledge could be used specially to benefit families of children with autism.

My discussions with parents had shown that they often developed routines for their children to reduce anxiety, although there were marked differences in how routine the parents own lives had become, and consequently, how rigid they were in day-today behaviours. FIT Science offered a fruitful framework to explore whether flexibility in thinking and behaviour was a contributing factor to perceptions of personal, and family stress. My thesis began exploring this question in a sample of typically developing adults in order to provide rationale for considering the role of cognitive and behavioural flexibility in family outcomes in the context of autism. Finding that perceptions of family functioning were indeed related to how people scored on FIT Science variables, I explored these associations further in an adult sample of individuals with High Functioning Autism and Asperger syndrome, and also with mothers of young children with autism. It appeared that FIT variables were particularly related to how mothers perceived their family environment, and also their own levels of personal, and parenting stress. With parenting stress being a key theme in the literature on autism and family life, the programme of research went on to develop and pilot an intervention based on FIT Science that was effective in helping mothers improve in their levels of depressive symptoms, and parenting stress. This is important since family variables, such as parental stress, are known to influence the course of child development. It is hoped that the intervention advanced by this thesis will provide parents with an engaging tool to unlock self-generated constraints when raising extraordinary children.

#### Abstract

This thesis used FIT Science (Fletcher & Stead, 2000) as a framework to study different aspects of family functioning. FIT variables measure the cognitive and behavioural characteristics of a person that mediate interpretations of events and attempts at coping with constraints. The research sought to examine whether scores on FIT variables explain differences in perceptions of family functioning and outcomes such as individual stress levels.

In the first questionnaire study, members of the general population (N=235) completed The FIT Profiler (Fletcher, 1999), which measures scores on FIT variables, and the Family Assessment Device (Epstein, Baldwin & Bishop, 1983), which measures family functioning across six dimensions. The study found that higher scores on FIT variables were associated with more positive experiences of the family. A similar pattern of results was observed in study two involving participants (N=52) with Autistic Spectrum Conditions (ASCs). The results of the studies suggested that FIT Science is a useful framework to study family functioning in diverse contexts.

Study three compared the stress and perceptions of family functioning of mothers of typically developing children (n=55), and children with ASCs (n=33). Mothers scoring high on FIT variables had better perceptions of family functioning, were less anxious and depressed, and also coped better with the demands of parenting.

Studies four and five explored whether FIT Science also offers a useful framework for promoting changes in family functioning and individual well being. Study four reported a randomized control trial of a FIT-Do Something Different (FIT-DSD) intervention, which was administered to mothers (n=13) of children with ASCs. The FIT-DSD intervention aimed at expanding behavioural flexibility and disrupting constraining habits. Study five reported a qualitative follow-up of the intervention group in study four.

The results of studies four and five suggested that the FIT-DSD intervention was a useful and novel tool to help mothers across a number of domains of family life. Relative to a wait-list control group (n=11), the intervention group reported moderate to large improvements in their levels of parenting stress, depression, relationship satisfaction and scores on the cognitive FIT variable Self-responsibility. Qualitative investigation also suggested that the intervention helped mothers develop feelings of control, self-esteem and self-efficacy.

The thesis suggests that FIT Science offers a fruitful framework with which to study and intervene with family functioning. Further research seeking to explore the use of FIT Science as a vehicle for family change is recommended. This may help promote better physical and psychological health for individuals struggling with their environmental and self-generated constraints.

#### Chapter 1

# Theoretical Framework: FIT Science and the McMaster Model of Family Functioning

#### 1.1. Introduction

The family is considered the place where 'most important things happen' (MacArthur, 2000 p.1). Based on this assumption, there is a large body of research exploring how the family environment influences its members. Many people are exposed to media portrayals of families featuring distorted family relationships, arguing, fighting, jealousy and rivalry. Whilst this may be entertaining, research shows that in reality, problems in family functioning are associated with several personal consequences for child and adult members. This includes increased risk of developing psychological conditions such as depression (Keitner & Miller, 1990), problems in early development for children (Cassidy, Parke, Butkovsky & Braungart, 1992; Katz & Woodin, 2002), juvenile delinquency (McCord, 1991), and poor outcomes in chronic health conditions (Stanton, 1999). Consequently, many models have been developed, which aim to advance knowledge of the key determinants of effective family functioning. The models delineate the contextual variables that influence family functioning, and also some of the processes that facilitate functioning across key domains. These models are based on a systems approach, which focuses on studying the family unit as a whole. Such models do not consider the personal characteristics of individual family members that might be related to how they cope with family stressors, perceive the functioning of the unit, and are affected by the family. Families are made up of individuals, each of whom is likely to hold different constructions about how the family functions and may have unique resources for coping. It is essential to explore the factors that differentiate people who cope well with family stressors from those who do not. The characteristics of individuals are likely to impact upon family functioning and outcomes such as individual stress levels.

The aim of this thesis is to explore whether FIT Science (Fletcher & Stead, 2000) variables are related to how individuals perceive their family functioning. FIT is an acronym for Framework for Internal Transformation or Flexible, Innovative and Trainable. The FIT framework posits that the differences between people's FIT levels determine how they feel and construe the world. According to FIT Science, people in the same situation vary greatly in how they perceive their circumstances. These perceptions are shaped by FIT variables, rather than objective or environmental differences that principally determine psychological outcomes such as levels of stress, anxiety and depression.

Families face many challenges over their life cycle such as marriage, pregnancy, illness, financial worries, relationship conflicts, death and so on. Coping with each of these challenges is likely to be influenced by extra and intra familial variables, and also the characteristics of individual family members. FIT Science suggests that there are a number of individual cognitive and behavioural strengths that are necessary to effectively cope with a range of life events, including those relevant to the family (Fletcher & Stead, 2000). This programme of research tests, for the first time, the utility of FIT variables in understanding the characteristics of individuals that might mediate perceptions of family functioning. This is exploratory research to evaluate a relatively new framework to see if it makes a contribution to understanding family functioning.

FIT Science has previously been applied in a broad range of areas to understand and intervene with how people think and feel about personal projects (Little, 1983) such as losing weight and changing eating habits (Fletcher, Hanson, Pine & Page, in press; Fletcher & Page, 2008, Hanson, 2008), stress (Fletcher, 2007c) and changing smoking habits (Pine & Fletcher, in press). On the face of it, it seems that FIT Science might also advance knowledge of the differences between individuals that influence how they perceive their families.

#### 1.1.1 The Programme of Research

The thesis aims to answer four specific questions:

- 1. Are personal strengths that are measured by FIT variables related to how people perceive their family functioning?
- 2. What is the relationship between how people perceive their family functioning, levels of self-reported depression and anxiety, and scores on FIT variables?
- 3. Can FIT variables advance knowledge of family functioning and outcomes such as parenting stress across diverse contexts?
- 4. To what extent might interventions targeting the development of personal strengths, measured by FIT variables, be effective in improving experiences of the family, and personal well being?

In order to answer the questions posed, this programme of research aims to draw and test theoretical synergies between an established model of family functioning and FIT Science. This chapter describes FIT Science and The McMaster Model of Family Functioning (Epstein, Bishop & Lewin, 1978). When describing the McMaster Model, attempt is made to highlight how FIT variables might compliment understanding of differences in how people perceive their families. In the next chapter (study one), the proposed associations between FIT variables and perceptions of family functioning are tested in a sample of members from the general population. The research then moves further, in study two, to test whether FIT variables can help understand family functioning in unique contexts. Study two specifically explores whether how adults with Autistic Spectrum Condition (ASCs) score on FIT variables is related to perceptions of family functioning. The third study reported builds on the findings of study two by considering whether FIT variables contribute to broader family issues. The study reported explores whether or not, relative to a control group, FIT variables play a role in how mothers of young children with ASCs perceive their family functioning and levels of personal (depression and anxiety) and parenting stress. The final phase of the research programme describes and reports quantitative and qualitative results of an

intervention based on FIT Science. The intervention was carefully designed and administered, in a randomized control trial, to test the practical utility of FIT Science for developing resilience in mothers of children with ASCs. The intervention focused on developing strengths measured by FIT variables and tested the effect of intervention on a broad range of outcomes including perceptions of family functioning, levels of depression and anxiety, parenting stress and the use of coping strategies.

#### 1.2. FIT Science

Why do some people seem to get on in life whilst others do not? Why do people in the same situation have very different constructions of their problems and ways of coping? FIT Science was proposed as a framework to understand variations in how people cope with the situations they encounter (Fletcher & Stead, 2000). FIT Science suggests that there are a number of individual cognitive and behavioural strengths that are important. These variables contribute to (1) how people perceive situations (2) analyze situational demands (3) the behavioural choices they make and (4) the outcomes they experience. FIT Science proposes that these characteristics can be objectively measured using The FIT Profiler (Fletcher, 1999). Due to their cognitive and behavioural strengths, people who score high on FIT variables have the potential to meet the demands of any situation. Their thinking is more likely to be relevant and this leads to more appropriate behavioural choices and ultimately, better outcomes and less life stress. It may be that individuals who score high on FIT variables are less guided by behavioural habits, which research suggests are major determinants of how people behave in different situations (Wood, Quinn & Kashy, 2002).

Fletcher and Stead (2000) describe the FIT framework as a simple way of defining and measuring the characteristics of people. The framework consists of five inner cognitive dimensions called the 'Constancies', which are summed together to form the FIT Integrity variable. In addition, there are fifteen outer or behavioural dimensions – measured in a novel manner, which captures the range of responses

people may use - which comprise FIT Behavioural Flexibility. FIT Science suggests that people who get on in different areas of life are likely to score high on both FIT Integrity and FIT Behavioural Flexibility. FIT Integrity, the Constancies and FIT Behavioural Flexibility will be described in turn below.

#### 1.2.1 FIT Integrity and the Constancies

FIT Integrity is comprised of five inner cognitive dimensions called the Constancies. The five Constancies are Awareness, Self-responsibility, Fearlessness, Conscience, and Balance.

#### 1.2.1.1 Awareness

Awareness is defined as the degree to which an individual monitors both their internal and external environment. The majority of people are guided by their behavioural habits and pay scant attention to feedback from the environment, from their own cognitions, or the actual goals they have. Low levels of Awareness are likely to lead to people failing to make full use of their personal resources. Awareness is about being awake and monitoring internal and external states and using feedback to guide actions, thoughts, feelings, and decisions, rather than relying on habit. According to FIT Science, only by being aware are individuals likely to make appropriate behavioural choices and change deliberately and for the better.

#### 1.2.1.2 Self-responsibility

Self-responsibility captures the extent to which a person takes responsibility for what happens to them and the world around them, irrespective of whether something is commonly considered within control. A person who is self-responsible is likely to take accountability for shaping their own world, as opposed to believing that external factors such as luck influence what can be achieved. In this way, Self-responsibility can be likened to locus of control. Individuals who are self-responsible are likely to play an active role in directing how their memories and experiences are stored so that the past does not exert control over the future. The individual actively shapes their world and sees this as a reflection of him or her self.

#### 1.2.1.3 Fearlessness

Fearlessness is facing unknown situations with the same confidence as familiar situations. Fear guides much of what people do, their actions, choices and decisions. Most people are not aware of this, or if they are, they feel unable to overcome fear. A person may not possess the necessary resources to confront their fear. Fearlessness is essentially about doing things because they are right and not because of worry about the social consequences of being different. This means feeling comfortable and confident outside of the behavioural comfort zone. Only then is a person likely to act with Integrity and not allow fear of social expectations and anxiety about uncertainties guide behaviour.

#### 1.2.1.4 Conscience

Conscience is a characteristic that helps a person tell what is right from what is wrong. A person who scores high on Conscience is likely to act ethically and never compromise morals in order to achieve things. Fletcher & Stead (2000) suggest that although each individual may be guided by a different ethical template, it is likely that most people consider the thoughts and feelings of others, respect and appreciate the views and right of others, and do not hold stereotypes or prejudices against particular groups of people when making choices about how to behave ethically.

#### 1.2.1.5 Balance

Balance is the ability to devote time to different areas of life. A person who scores high on Balance is less likely to be absorbed by any one area of their life such as work, although they will be able to prioritize and allocate their time to more important tasks when need be. No one area of life is likely to suffer from this. To the contrary, a person who scores low on Balance may lose focus and become too absorbed in a specific aspect of their life. For example, ignoring work commitments over the family.

According to FIT Science, the five Constancies form a person's Integrity base. Integrity (and the Constancies) guide thought about life events and behavioural responses. If the Constancies are all in harmony with each other, a person is likely to cope with the demands and constraints present in day-to-day life and generally achieve things by behaving appropriately. Having a solid and consistent Integrity base therefore means that an individual should behave, or at least has the potential to behave appropriately in any situation. This is because he or she perceives the situation accurately. Having an accurate perception of reality is essential to cope with situations and to find a way of moving past the personal consequences of negative life events. Perceptions of reality are continually referred to in common theories proposed for understanding problems such as depression (e.g. Beck, 2002). In conditions such as depression, it is believed that people form unrealistic and negative views of themselves and the world around them, and these perceptions influence subsequent thinking and behaviour. A person with a strong Integrity base on the other hand is likely to have a grasp over reality and uses this understanding of situations to make behavioural choices that are effective. These choices might include relying on habit if a particular habit is still effective in dealing with a situation. On the other hand, a new response may be required.

#### 1.2.2 FIT Behavioural Flexibility

FIT Science proposes fifteen different behavioural dimensions. These include behaviours that must be in a person's behavioural repertoire if he or she is to be effective across different situations. These behaviours are not considered as fixed traits. This is because Behavioural Flexibility is essentially seen as being trainable, where as traits are viewed as characteristic of the person, which tend to become more stable with age (e.g. see Caspi & Roberts, 2001). Fletcher & Stead (2000) on the other hand propose that through expanding a person's behavioural repertoire, over time, the Integrity base and the Constancies are likely to also change.

The FIT Profiler measures the extent to which a person demonstrates both ends of a behavioural continuum i.e. can be both an introvert and an extrovert depending on the situation. The behaviours measured by the FIT Profiler include (1) unassertive-assertive (2) trusting of others-cautious of others (3) calm/relaxed-energetic/driven (4) reactive-proactive (5) definite-flexible (6) predictable-unpredictable (7) risk taker-cautious (8) behave as expected-behave as you wish (9) spontaneous-systematic (10) single-minded- open-minded (11) introverted-extroverted (12) conventional-unconventional (13) individually centered-group centered (14) firm-gentle and (15) lively-not lively.

#### 1.2.3 FIT Science in Research

FIT Science makes three important assumptions, which this thesis will also test and explore further in the context of families:

- Individuals who score high on FIT variables are likely to perform better in different areas of life. This is because they are more adaptable in the way they think and solve problems. This thesis will explore whether or not people who score high on FIT variables perceive their families as functioning more effectively.
- 2. There is likely to be a close link between the Constancies and depression and anxiety. People scoring high on the Constancies are expected to report lower levels of depression and anxiety. This is because they have greater cognitive integration, for example, they are more aware and self-responsible. This means having an accurate perception of reality and taking responsibility for what happens in life. Scoring high on the Constancies also means that people may be less fearful and experience less anxiety related to the demands of different situations. This thesis will explore whether or not people who score high on FIT variables report lower levels of depression and anxiety.
- 3. Personal strengths in the cognitive and behavioural dimensions of FIT Science can be trained. This is achieved by expanding Behavioural Flexibility. By disrupting daily habits that constrain cognitions, it may be that people can be helped in becoming more adaptable in their thinking and behaviour. FIT

Science proposes that changes in behaviour might act as a lever to changes in the Constancies, which guide the behavioural choices a person makes, and ultimately leads to better coping with life events. This thesis tests whether or not expanding the behavioural repertoire of mothers leads to better outcomes when raising a child with an ASC.

A number of research studies have been carried out to test these assumptions in areas outside the family functioning domain. In the area of occupational health for example, FIT Science suggests that work stress is inherently within the person and results from their constructions of the situation and the marshalling of personal resources for coping. Fletcher (2007a), for example, reports a study of 391 managers working for an international bank who completed both The FIT Profiler and The Work-FIT Profiler (Fletcher, 1999). A second sample of 47 supermarket checkout workers was also used for comparison purposes. The study found that employees who scored high on FIT variables, especially in FIT Constancies, reported less work related stress in a range of different areas including satisfaction with the company, work demands, work supports, work relationships, control, goal acceptance and strain. People who scored high on the Constancies appraised their work environment differently to those scoring low on these FIT variables. Importantly, the study also revealed that variations in the scores of work demands and supports in the supermarket workers, who were all doing essentially the same objective jobs, were as great as the differences between all jobs in the bank. This is despite the fact that employees in banks were employed at different levels and were based in different parts of the world. The results suggest that person-based variables might influence how people construe the world around them, the way they interact with the world, and the level of success or stress subsequently experienced. The differences between people's FIT Science scores were more important than the differences in their work environment (a result supported by Morrison, Payne & Wall, 2003).

Based on the core assumptions of FIT Science, research studies have also tested the proposed relationship between how people score on FIT variables and their level of personal stress (throughout this thesis, 'personal stress' will refer to levels of depression and free-floating anxiety). Depression and anxiety are both measured by The FIT Profiler in the Thoughts and Feelings Scale. Fletcher (2007b) describes a study involving 351 members of the general population, testing the association between scoring high on FIT variables and the experience of lower levels of personal stress. This study found that scoring high on FIT Integrity and FIT Behavioural Flexibility was associated with lower levels of self-reported depression and anxiety. For example, the correlation between FIT Integrity and depression was reported as -0.51 and with anxiety the correlation was -0.64. A similar pattern of results was reported for the association between individual Constancies and levels of personal stress. These findings suggest that the cognitive and behavioural characteristics of people, measured by The FIT Profiler, are related to how they deal with and are personally affected by life events.

The third assumption of FIT Science is that cognitive and behavioural strengths should be trainable. This is achieved by expanding a person's behavioral repertoire, which may, overtime, also reshape a person's thinking. For example, Fletcher (2007c) reports the results of a FIT-Do Something Different intervention, which aimed to reduce stress in 34 employees who were experiencing high levels of depression and or anxiety. Participants either volunteered to take part in the study or were referred by their organization. The FIT-Do Something Different intervention involved participants trying a task each day over the course of a month to expand their general repertoire of behaviour. The idea behind the intervention is that by expanding behaviour, a person may bring about deeper changes in the Constancies. This helps the person to manage the situations he or she encounters more effectively and in turn may reduce the level of stress experienced. The study found that the intervention was successful in bringing about changes in scores on The FIT Profiler. Over the course of the study, mean scores on FIT Integrity went from 58.5 to 67.3 and Behavioural Flexibility increased from 14.7 to 28.9. These were

significant increases in cognitive and behavioural strengths, which were significantly associated with a decrease in levels of depression and anxiety. For example, prior to commencing the intervention, 18 individuals had depression scores in the clinical range. This fell to only 4 individuals scoring in the clinically depressed range on the Thoughts and Feelings Scale after completing the intervention. This study further supports the association between FIT Science variables and personal stress, and also suggests that strengths in the cognitive and behavioural dimensions of FIT Science are trainable.

More recently, in a series of studies, Fletcher and his colleagues have studied the role of FIT variables in a range of health outcomes. For example, Hanson (2008) reports that people who score high on FIT variables are characterized by lower levels of depression and anxiety, and also perceive their work, life and personal projects (Little, 1983) significantly more positively than those who score low on FIT variables. Based on these findings, Fletcher et al (2010) developed a FIT-Do Something Different intervention and found this was effective in helping people improve their physical well being, as measured by changes in Body Mass Index (BMI). The research found a dose-response relationship between FIT Behavioural Flexibility and reductions in BMI (Fletcher et al, 2010). Qualitative exploration of peoples attitudes towards the FIT-Do Something Different intervention also confirmed that through engaging with the intervention materials, people were helped in changing their behavioural habits, which allowed them to develop more effective behaviours; changing their eating habits and exercising more. Fletcher and Page (2008) also showed that the effect of the FIT-Do Something Different intervention was not simply due to the demand characteristic of having any intervention. The observed changes in BMI were seen only in the FIT-Do Something Different group and not in a narrative control group.

The wide application of FIT Science to understand how people perform in different areas of life suggests that this framework might also help explain how people perceive their family functioning. Based on the research described, people who score high on FIT variables might perceive their family as functioning more effectively. To understand why, it is necessary to define the concept of family functioning. In the next section, a leading framework, the McMaster Model of Family Functioning, will be described. Attempt will also be made throughout to delineate why FIT variables might be related to how people perceive their family functioning.

#### 1.3. The McMaster Model of Family Functioning

#### 1.3.1 A Systems Model

The McMaster Model of Family Functioning is an established model of family assessment and treatment (Epstein & Bishop, 1981). It was developed over 20 years of research with non-clinical families (those with members free from any psychiatric disorders) and research into family therapy (Ryan, Epstein, Keitner, Miller & Bishop, 2005). Viewing family functioning as a multidimensional construct, the McMaster Model does not claim to cover all aspects of family functioning. The model attempts to highlight the most important areas for the emotional and physical well being of family members (Ryan et al, 2005). No single dimension of family functioning is the foundation of the model as the authors suggest this was a limitation of earlier conceptualizations (Epstein et al, 1978). In each area of family functioning described, the McMaster Model delineates the functioning continuum from 'most effective functioning' to 'most ineffective functioning'.

According to the McMaster Model, the family has three primary goals: the social, psychological and biological development of its members (Epstein et al, 1978; Ryan et al, 2005). In trying to accomplish these objectives, families need to carryout tasks in three areas (1) the basic task area (2) the developmental task area and (3) the hazardous task area. The very essential tasks required of the family are captured in the basic task area. This includes things that ensure the physical survival of family members such as providing food and shelter. The developmental task area captures

issues related to the development of the family over time. Developmental tasks for the individual relate to crises that arise at different stages of life i.e. childhood, adolescence and adulthood. Family level crises on the other hand relate to issues such as marriage and pregnancy (Ryan et al, 2005). Finally, the hazardous task area encompasses dealing with crises such as illness and income loss. Families who are unable to resolve issues arising in each of the task areas are proposed to be more vulnerable to developing clinically relevant problems (Ryan et al, 2005).

The McMaster Model is a systems model of family functioning, as are other leading models in the area (e.g. The Circumplex Model of Marital and Family Systems, Olson, Russell & Sprenkle, 1989). This is an established approach to studying the family, originating in the 1940's. Systems approaches to family functioning see the family as an open system that interacts with external groups such as extended family, friends and the community. The family system is also seen to be made up of sub-systems such as marital and parent-child dyads (Ryan et al, 2005). Families are believed to have hierarchical structure. Families are formed of smaller systems in their own right embedded within a larger system. Each sub-system will have its own boundaries that family members learn through repeated interactions with one and other. Although hierarchically organized, the sub-systems within the family are not thought to have a unidirectional effect on one and other (Cox & Paley, 1997).

In viewing the family as an open system, models such as the McMaster Model make some fundamental assumptions, each of which will be described below:

- 1. Wholeness. The family is seen as more than the sum of its parts and so any part of the family cannot be understood by isolating it from another (Cox & Paley, 1997; Ryan et al, 2005).
- 2. Parts of the family are interrelated and transactional patterns between parts of the system can be viewed as shaping the behaviour of its members (Ryan et al, 2005).
- 3. The family responds to feedback from its members or the environment to ensure survival. Cox & Paley (1997) expand on this with reference to

adaptive self-stabilization and adaptive self-organization. Adaptive self-stabilization refers to the ability of the family system to maintain stability in response to changes in the environment. This allows the family to make internal changes to prevent environmental conditions from affecting its internal workings. Adaptive self-organization is the ability of the family to change in response to constraints placed on existing patterns of functioning at any level of the system. This property recognizes that systems change overtime and that adaptations may make the system more complex and vulnerable as it attempts to cope with natural transitions (Cox & Paley, 1997).

#### 1.3.2 Dimensions of the McMaster Model of Family Functioning

The McMaster Model of Family Functioning is comprised of six dimensions of family functioning. The six dimensions of the model are: problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control. In the following section each of the dimensions of the model is summarized. The role of FIT Science variables in understanding why some families work well, whilst others do not, is also explored. When describing the dimensions of the McMaster Model, the terms effective or healthy and ineffective or unhealthy will be used interchangeably. The overview of the model is based on Epstein et al (1978); Miller, Ryan, Keitner, Bishop and Epstein (2000); and Ryan et al (2005).

#### 1.3.2.1 Problem Solving

Problem solving refers to the ability of the family to overcome problems to a standard that maintains family functioning. By 'problems' the model is referring to issues that threaten either or both the functional capacity and integrity of the family. Problems that are ongoing but do not interfere with family well being are not considered. The McMaster Model proposes two types of problems a family might encounter, instrumental and affective. Instrumental problems arise in relation to fulfilling the basic task; ensuring day-to-day survival through resources such as

food, shelter and money. Affective problems relate to dealing with emotions and feelings.

The McMaster Model describes a series of steps involved in effective problem solving in instrumental and affective areas. First, a family must recognize a problem and discuss or communicate the problem with appropriate family members. Family members must then work on developing a number of alternative solutions to the problem and select the most appropriate solution from these. The selected solution then needs to be implemented and monitored. Finally, the family needs to evaluate the usefulness of the selected solution and review the effectiveness of the overall problem solving process. The model recognizes that not every problem requires all the family, or any of the members, to follow all of the above steps. However, families who are effective at problem solving will tend to approach the task in a systematic manner. Less effective problem solvers vary in their approach and it becomes clear where the family is failing to apply the principles of problem solving.

According to the McMaster Model, families who function effectively may have small, unresolved problems. These problems will not threaten the family in any way. Healthy families identify instrumental and affective issues in good time and are open in their communication, leaving no instrumental problems unresolved. There may be a few affective problems the family was unable to tackle but in general, through use of effective problem solving processes, the healthy family manages to successfully overcome the issues it faces. The model proposes that only families functioning exceptionally well will however be able to engage in the evaluation of the problem solving process.

#### 1.3.2.1.1 FIT and Problem Solving

Effective problem solving might be directly related to how people score on FIT variables. Family members who score high on Awareness might be better at recognizing potential threats to family functioning. This is because these individuals are likely to monitor their internal and external environment more carefully. When a threat has been recognized, people scoring high on Self-responsibility and Fearlessness are anticipated to be better at communicating problems to other family members. A self-responsible person is more likely to take responsibility for what happens to them rather than leaving things to luck or chance, or hoping that problems will somehow resolve themselves. A person scoring high on Fearlessness may also not be as constrained by fear of how other members of the family will respond to disclosure of instrumental or affective problems. The fearless person should act based on what is right to do i.e. tell others about the problem. The very fact that people scoring high on FIT Integrity and FIT Behavioural Flexibility are unlikely to be as constrained by automatic habits might mean that they are more creative problems solvers. It would also be predicted that a person scoring high on FIT variables might think and behave more appropriately, leading to more effective problem solving across a range of problem types. This is because scoring high on FIT variables inherently means that a person can more adequately change to cope with the demands of different situations. A high level of Awareness also makes it more likely that the person will be effective at evaluating behavioural choices.

#### 1.3.2.2 Communication

Communication is the second dimension in the McMaster Model and refers only to the verbal exchange of information within the family. Although it is commonly understood that communication has both verbal (speech) and non-verbal aspects (e.g. gesture, intonation), the McMaster Model uses a narrower definition. This is in part due to difficulty in the measurement of non-verbal communication and because non-verbal acts maybe more open to misinterpretation. The McMaster Model is also concerned with communicative patterns within the family as opposed to the style of communication employed by individual members. By using this definition of

communication, the McMaster Model aims to maintain practical utility in both research and clinical settings.

The McMaster Model classifies information exchange into two categories, instrumental and affective. The model suggests that families experiencing difficulty in communicating affective issues can function well in instrumental communication but it is rare for the reverse to be true. To study communication within the family, it is important to acknowledge two additional dimensions of information exchange. The dimensions are clear versus masked and direct versus indirect. These dimensions can be thought of as continuums. The clear versus masked continuum considers whether utterances from family members state exactly what is meant or whether information exchange is vague. The direct versus indirect continuum is concerned with whether utterances are delivered to their target or to a third person. Interactions within these dimensions allows for four styles of information exchange within the family:

- 1. Clear and direct- the most effective style of communication. The content and target of the message is clear.
- 2. Clear and indirect- the content of the message is clear but it is not clear who the target is.
- 3. Masked and direct- the content of the message is unclear but the target is clear.
- 4. Masked and indirect- the content and the target of the message are unclear.

Effective styles of communication are represented by clear and direct information exchange. In contrast, the most ineffective style of communication within a family would be masked and indirect. It is acknowledged however that effective or healthy communication might involve some occurrences of masked or indirect exchange, usually in areas of conflict, although otherwise the family communicates in an effective manner.

#### 1.3.2.2.1 FIT and Communication

It is expected that a person scoring high on Self-responsibility, Conscience and Fearlessness might communicate more effectively with other family members. This is because a person characterized by these strengths is more likely to take responsibility for making his or her thoughts and desires clearly understood. A person scoring high on Self-responsibility may be less likely to expect other people to understand their desires and might be better at effectively communicate things. A person scoring high on Conscience might be more sensitive to the feelings of others and less likely to use communicative styles that cause others to be confused or hurt by behaviour. It is also expected that scoring high on Fearlessness is relevant to family communication. A person scoring high on Fearlessness might have more courage to be clear and direct in their communicative interactions and be able to effectively deal with any conflict arising from difficult discussions e.g. those around affective issues.

#### 1.3.2.3 Roles

Roles are the recurring patterns of behaviour of family members by which they carry out their family functions. The McMaster Model identifies five basic functions of the family. The five functions are (1) the provision of resources (2) nurturance and support (3) adult sexual gratification (4) personal development and (5) the maintenance and management of the family. The McMaster Model stresses the importance of considering role allocation and role accountability. Role allocation looks at the family's pattern of assigning responsibility- whether this is appropriate for the individual (i.e. age and suited to skill) and if roles are assigned explicitly and clearly. It is also essential to assess whether family members are happy with the structure of role allocation and if there is flexibility in the re-allocation of roles. Role accountability explores the methods in place for evaluating whether the allocation of roles allows for the fulfillment of family functions and if there is a corrective mechanism to rectify the misallocation of tasks.

According to the McMaster Model, families that function well in this area mange to fulfill their basic functions by allocating roles clearly and having an accountability mechanism in place, although the latter will not always be true. There may be times where families have difficulty in achieving a given function but this will not hinder the effective functioning of the system overall. The model suggests that some family structures call for one member assuming more roles than others but this may not be unhealthy for functioning. However, in the most effective families, other family members will be willing to share household tasks.

#### 1.3.2.3.1 FIT and Roles

How individual family members score on FIT variables may influence how they assign and monitor the allocation of roles within the family context. A person scoring high on Conscience might be more concerned to ensure that other family members are happy with the tasks assigned to them. Furthermore, scoring high on Awareness could mean that a person has the information required to make a decision around whether the allocation of tasks suits another's skills. A person scoring low on Awareness on the other hand might be more likely to allocate tasks to family members who are not the most able to carryout a role effectively and efficiently. Families with members scoring high on FIT Integrity and Behavioural Flexibility might also be more able and comfortable with re-assigning family roles. This is because people might be more comfortable outside their comfort zone and maybe less likely to find it challenging to break out of their past behavioural routines and habits.

#### 1.3.2.4 Affective Responsiveness

Affective responsiveness refers to the ability of family members to respond to stimuli with a reasonable level and appropriate type of emotion. This dimension is concerned with a family's qualitative and quantitative range of emotional responses. The model identifies two categories of emotional responses, emergency (e.g. fear and anger) and welfare (e.g. love and joy). The model mainly addresses whether family members have the capacity to respond emotionally in both of these contexts.

Healthy functioning in this dimension is characterized by the ability to exhibit the usual range of emotions that are tailored to suit the contexts (emergency and welfare) in which they are expressed. Families doing well in this area will generally have the capacity to exhibit the full range of emotions that will be expressed appropriately, although there may be rarer instances where family members overreact and times when they do not react at all.

## 1.3.2.4.1 FIT and Affective Responsiveness

It may be that key FIT variables will also be related to the affective responsiveness of family members. Awareness might be important here for a person to be aware of affective stimuli and select an appropriate response. Families characterized by people who are cold or seem not to respond at all might include members who are simply not aware of affective stimuli or are unable to monitor their own internal state. Conscience might also be an important cognitive strength for people to recognize when they have responded inappropriately and adapt their behaviour to deal with the distress caused to others.

#### 1.3.2.5 Affective Involvement

Affective involvement refers to the degree to which the family shows interest in individual family members. The McMaster Model is primarily concerned with how this interest is expressed. The McMaster Model identifies six styles of involvement with other family members:

- 1. Lack of involvement here family members show no interest in each other and act as if they are simply sharing the same environment.
- 2. Involvement devoid of feeling- when family members show some interest in each other, usually when demanded and is intellectual in the main.
- 3. Narcissistic involvement- occurs when family members show interest in others but only to the extent that involvement with others is egocentric.
- 4. Empathetic involvement- reflects true interest in the lives of other family members.

- 5. Over involvement –occurs when family members become too concerned with and intrude in the lives of others.
- 6. Symbolic involvement- although rare, occurs when relationships become so enmeshed that it is difficult to differentiate between two family members.

# 1.3.2.5.1 FIT and Affective Involvement

According to the McMaster Model, the empathetic style of involvement is the most effective for family functioning. It will also be the case in healthy families that members behave reasonably egocentrically or become more involved in the lives of other family members, although these instances may not reflect day-to-day family processes. The latter might reflect the level of Behavioural Flexibility or Awareness of individual family members. This allows for the individuals to recognize that some patterns of involvement are not healthy for the family and trying to adapt their behaviour to show appropriate involvement with others. Having a good sense of Balance between importance, satisfaction and effort might also be necessary to recognize when to become more involved in the lives of others.

#### 1.3.2.6 Behaviour Control

The final dimension of family functioning incorporated within the McMaster Model is behaviour control. This dimension is concerned with how a family deals with controlling behaviour in three situations: dangerous situations, when expressing psychological needs, and issues surrounding socializing behaviour. The model identifies four styles of behaviour control:

- 1. Rigid- rules are set and there is no room for negotiation around these.
- 2. Flexible- rules are set, which the whole family is comfortable with and there remains room for negotiation and change.
- 3. Laissez-faire- there are very few or no rules in place or standards of behaviour.
- 4. Chaotic behaviour control –occurs when the family shifts between the former three styles and members are unsure of when rules apply and how much negotiation, if any, is possible.

The McMaster Model suggests that the flexible style of behaviour control is most effective. There may be times when family members fail to implement or follow family rules but there will nonetheless be a general consensus about what is acceptable.

#### 1.3.2.6.1 FIT and Behaviour Control

For families to be flexible in their style of behaviour control and for individuals to be able to respond to these changes, it is likely that people may need to be comfortable with change. FIT Behavioural Flexibility may be particularly relevant in this context. A flexible person might be better able to adapt according to changes in external boundaries and rules. Flexible thinking, as reflected in high levels of Integrity, might also allow family members to be adaptable in when and how they implement family rules. For example, regulating behaviour in the home- as opposed to in public places - might call for a different set of behaviours and different thinking. For this flexibility to exist, it is likely that individual family members will need to be generally adaptable in their ways of thinking and behaving.

#### 1.4. Intervening with families

There are many reasons to think that FIT variables might be related to how families function in areas of the McMaster Model. This is primarily due to the strengths of individual family members that may be related to how they think about and attempt to cope with different situations. If there are reasons to believe that FIT variables may be related to family functioning, as described by the McMaster Model, it may be valuable to explore this more in the context of family interventions. Problems in family functioning are known to influence the well being of family members and so it is important to consider the framework for developing family resilience advanced by both the McMaster Model of Family Functioning and FIT Science.

## 1.4.1 The McMaster Problem-Centered Systems Approach

The McMaster Model of Family Functioning has come to form part of the common clinical and research assessment of family functioning (Epstein et al, 1978). Since its introduction, the McMaster Model has been used as the theoretical base in the development of a range of tools used to assess overall family functioning or to highlight difficulties in any one area of the model. Instruments developed from the model include the Family Assessment Device (Epstein, Baldwin & Bishop, 1983), the McMaster Clinical Rating Scale (Miller et al, 1994) and the McMaster Structured Interview of Family Functioning (Bishop, Epstein, Keitner, Miller & Zlotnick, 1980). The Family Assessment Device in particular, which is a self-report measure of family functioning across the dimensions of the McMaster Model, has been extensively used across research studies. Swain, Harrigan and Woog (1995) state that the Family Assessment Device is one of the most widely used self-report measures of its kind. Its use in research is primarily due to the measure being time and cost efficient and correlating well with both independent ratings from professionals, and other measures of family functioning (Barney & Max, 2002; Miller et al, 1985).

The McMaster Model is also used in clinical practice to intervene with families and offers a problem-centered systems therapy approach (Ryan et al, 2005). Ryan et al (2005) describe the major stages of this approach as assessment, contracting, treatment, and closure. Each of these 'macro' stages is also comprised of sub-stages. Family members take an active role in each stage of treatment and the therapist acts as a catalyst for bringing about change in the family system. Typically, having understood the issues present within the family in the assessment stage, all family members would be involved in the therapy stage, although on some occasions, it may be clinically necessary to include only one or two family members. Inclusion of the entire family is necessary in treatment when viewing the family as a system (Ryan et al, 2005). The treatment itself focuses on changing the current behaviours of family members, which is believed to reflect real change in attitudes, desires, cognitions and so on. The therapist uses two main tools to achieve this, task setting and techniques to promote change. In task setting, the therapist would typically set

a family a task to achieve between therapy sessions and work on evaluating how well the task was executed in the next meeting. The task itself would try to present a change in the right direction. When assigning tasks, the therapist fosters the thought that changing behaviour is much more difficult than developing new behaviours. Therefore, a wife who wants her husband to stop criticizing her all the time might be asked to agree on something her husband could do to be more supportive e.g. he could say one good thing about her everyday until the next time they meet with the therapist. Tasks might also be set that are directly related to improving functioning in a problem area. For example, to improve family communication, a family might be asked to ensure they spend three minutes each day providing each member the opportunity to discuss positive personal issues with others. In therapy sessions the clinicians also use a range of techniques to facilitate behavioural changes and might also work on reshaping the cognitions of family members. Finally, therapists will also observe and challenge any dysfunctional transactional patterns between family members, for example, scapegoating. These patterns of behvaiour may not cause problems in family functioning but may prevent beneficial change (Miller et al, 2000; Ryan et al, 2005).

Research supports the effectiveness of family therapy as an approach to help families facing diverse challenges including coping with pervasive developmental disorders, schizophrenia and affective disorders (Pinsof & Wynne, 1995). However, a meta-analysis of marital and family therapy including 163 studies found that whist family therapy is effective, it does not produces more favourable results than individual therapy (Shadish, Ragsdale, Glaser and Montgomery, 1995). Moreover, the high cost of family therapy has to be weighed against the chance of nonengagement with therapy. Research into the effectiveness of family therapy for adolescents for example has shown that the nature of the therapists perceived skills influences treatment attendance and engagement (Karver, Handelsman, Fields & Bickman, 2005). Furthermore, early on Nichols (1987) stated that whilst family therapists need to acknowledge that the lives of family members are interrelated and are usefully studied and intervened with from a systems approach, the field as a

whole is placing less emphasis on the psychology of the individual. Nichols (1987) stated that 'the contemporary trend is so abstract that there is little room for human experience, for understanding, for personal responsibility, or for enhancing people's own ability to solve their own problems (p.10). Nichols (1987), drawing on personal experience as a family therapist described problems associated with using techniques to change the nature of interactions between family members, which may only bring about superficial and short-term changes in behaviour. Nichols (1987) suggested that lasting change in families only arises when there is a real change in the individual members and their ability to relate to each other. Although there is some evidence to support the effectiveness of family therapy, this approach is therefore limited by overemphasis on the interactions between family members and less focus on the individual's resources for coping.

## 1.4.2 The FIT-Do Something Different Intervention

The limitations of family therapy described above might be addressed by using approaches targeting the development of strengths in individual family members. These approaches, as Nichols (1987) suggested, might result in improving the ability of people to solve their own problems. Many approaches to family therapy, including the McMaster problem-centered approach, work on changing the nature of interactions between family members. Whilst useful, the long-term effectiveness of family therapy has not been explored. It may be that after completing therapy, people slip into their old habits of interacting with others and have difficulty in using learning to tackle different types of family problems.

FIT Science might offer an equally suitable and perhaps more practical approach to intervening with family functioning. Fletcher and colleagues have explored the benefits of expanding people's daily behaviours on a range of outcomes. For example, Hanson (2008), and Fletcher and Page (2008) found that by disrupting people's daily habits, they can be helped in increasing Behavioural Flexibility and thinking more flexibility, as noted in changes in scores on FIT variables. Changes in FIT variables in these studies were associated with helping people reduce their

levels of personal stress and tackling issues with fairly intractable prognoses, such as obesity.

FIT Science recognizes that people form behavioural habits that become entrenched and guide future thinking and responding. Behavioural habits can therefore restrict a person's ability to respond appropriately in future situations he or she encounters. Research shows that past behaviour is the best predictor of future behaviour (Ouellette & Wood, 1998). FIT Science proposes that by helping people disrupt their daily habits and expand their comfort zone of behaviour, changes in the way people think about and construe life events may be facilitated. The FIT-Do Something Different intervention is the tool for promoting changes in how people score on FIT variables and perceive things.

The FIT-Do Something Different intervention is a flexible approach to intervene with people and can be tailored to suit the needs of distinct groups. Typically, the FIT-Do Something Different intervention would require people to expand their daily behaviours. This might be through disrupting habits and by also trying new behaviours. When people change their way of responding across situations, they are likely to experience different thoughts and feelings and may also evoke different, and more positive responses from others. In this way, overtime, a person may become more motivated to change the way they deal with the situations they encounter and develop confidence in trying new ways of responding. By focusing on broad behavioural change, the intervention aims to promote coping with a range of life events and not just isolated behaviours or problems, which are often the focus of other types of interventions.

When behaviours are repeated they become habitual or automatic and are triggered by the environment in which they were formed (Verplanken & Orbell, 2003). In the context of the family, other family members are themselves also likely to trigger automatic or habitual patterns of responding, as well as the triggers provided by specific events. It is this automaticity in responding that is difficult to change as

Ryan et al (2005) acknowledge in saying that new behaviours are easier to form than changing problem behaviours. The FIT-Do Something Different intervention directly addresses this resistance of dysfunctional patterns of behaviour to change and might therefore be well suited to improve how people view the family also.

Importantly, the FIT-Do Something Different intervention only uses the person as a catalyst to change. There is very little professional involvement in the intervention, which makes it well suited to groups who are hard to engage in therapy. Results are also not influenced by the degree to which a person forms a relationship with the therapist. In this way, the responsibility for change lies with the individual. Once an intervention has been developed to help distinct groups, individuals can be given intervention resources and responsibility for engaging with change. Benefits of the intervention can also be measured using objective measures of e.g. stress, family functioning and so on. The FIT Profiler also allows for examining the degree to which changes in objective outcomes are related to the development of personal strengths brought about by the intervention. The approach offered by FIT Science to intervene with families might therefore address many of the limitations of family therapy.

# 1.5. Summary

Each member of a family is unique and is likely to hold a distinct perspective on family strengths and difficulties. It is important to understand the variables that influence how people perceive their family functioning. These variables are likely to be related to how people cope with the family environment and how they are affected by problems in family life. This chapter has explored the role that FIT variables might play in how people perceive their family functioning. It was proposed that people scoring high on FIT variables might be characterized by strengths that facilitate functioning in areas of the McMaster Model. In the following chapter, a study is reported, which tests the association between how people perceive their family functioning and scores on FIT variables. The study will address whether or not person-based variables influence how people construe their families.

Research of this nature is essential in light of the limitations of systems approaches to intervening with families.

## Chapter 2

Study One: The relationship between FIT Science variables and family functioning

#### 2.1. Introduction

This chapter reports a study exploring the relationship between FIT variables and family functioning. This research could advance knowledge of the broader characteristics of families that enable them to work well. The study aims to explore the following questions:

- 1. Are scores on FIT variables related to how people perceive their family functioning? This is important because established models of family functioning are based on systems approaches to studying the family. The systems approach pays scant attention to the personal resources of individuals for coping. This research aims to test whether characteristics of individuals are also important to consider.
- 2. What is the relationship between how people perceive their family functioning, levels of depression and anxiety and scores on FIT variables? Research suggests that problems in family functioning are related to psychological distress in family members (Keitner & Miller, 1990). This study explores whether or not FIT variables mediate the association between family functioning and personal stress. This could shed light on the characteristics of people that protect them from being personally affected by the family.
- 3. What is the relationship between how people score on FIT variables and family habits? Problems in family functioning arise when units develop dysfunctional behaviours across key domains of functioning. These behaviours, overtime, become difficult to change and are often the direct or indirect target of family interventions (Nicholas, 1987). Based on the association between FIT variables and behaving appropriately, the study explores whether or not the types of habits present in families are related to how people score on FIT variables.

## 2.2. The Study

# 2.2.1 Hypotheses

The study has four specific hypotheses:

- 1. People scoring high on FIT variables (measured by The FIT Profiler) will report fewer problems in family functioning (measured using the McMaster Family Assessment Device).
- 2. It is expected that FIT variables will mediate the relationship between family functioning and personal stress.
- 3. It is expected that FIT variables will be related to the types of habits family members report in areas of the McMaster Model of Family Functioning. Family habits will be measured using the Family Habit Assessment tool, which will be described in the method section. People scoring high on FIT variables are expected to report more effective and fewer ineffective family habits.

#### 2.3. Method

#### 2.3.1 Participants

Two hundred and thirty-five (66 males and 169 females) people from a wide range of backgrounds took part in this study. A further twenty-nine people expressed interest in taking part in the research but did not complete the study (achieving an 89% response rate). Just over 69% of participants were recruited and volunteered to take part in the study via social networking sites. A further 30.6% of participants were undergraduate students. The majority of participants were aged 18-21 (30.6%), 22-30 (26%) or 41-50 (20.9%). Most participants were White British (60.4%) or Indian (17.4%), although there was also a mix of people from other ethnic backgrounds. Just over 67% of people described their current family structure as nuclear. A further 9.4% described their family as extended (including grandparents and so on), 9.8% of people were in a single-parent family, 5.1% had a reconstituted (consisting on non biological parents and or siblings) family structure, 4.3% of participants described their family structure as other, and finally, 10 participants did not disclose information about family structure.

#### 2.3.2 Procedure

This was a questionnaire study. Participants were recruited by placing information about the study on social networking sites. Those interested in taking part contacted the researcher to obtain a copy of the study materials, which were mailed out with a self-addressed envelope. Some participants were students. Students were recruited by using the research participation system at the researchers university and received study credit for taking part. After expressing interest in taking part in the study, students met with the researcher who gave them a copy of the questionnaire pack. Students had two days in which to complete the questionnaire pack and return it to the researcher.

#### 2.3.3 Questionnaire Measures

The questionnaire pack completed by participants consisted of four sections. The first section asked various demographic questions including participants age, sex and family structure. The questionnaire pack also contained a section with the Family Assessment Device (FAD), The FIT Profiler, and what is termed here the Family Habit Assessment Tool (FHAT). The respective questionnaires can be found in appendices a-c.

#### 2.3.3.1 The Family Assessment Device

The Family Assessment Device (Epstein et al, 1983) is a self-complete, 53-item measure of family health and pathology over the six areas of the McMaster Model of Family Functioning. The Family Assessment Device is used to identify families requiring clinical follow-up in one or more areas of family functioning (Bihun, Wamboldt, Gavin & Wamboldt, 2002). Family members rate the extent to which they agree with items using a 4- point scale ranging from 'strongly agree' to 'strongly disagree'. Specific items pool together to highlight the state of family functioning in the six areas of the McMaster Model and in general functioning (Ryan et al, 2005). General family functioning is not explicitly a dimension of the McMaster Model. This scale is included for research purposes and provides an overall snap

shot of family health and well being. The general functioning scale is not intended to form part of the clinical assessment of families (Ryan et al, 2005).

The Family Assessment Device has sufficient test-retest reliability and yields consistent results across different types of families (Epstein et al, 1983; Miller, Epstein, Bishop & Keitner, 1985). Furthermore, Miller et al (1985) found that compared with an independent clinical rating, the instrument reliably differentiates between clinical and non-clinical families. Scores on the Family Assessment Device also correlate well with other measures of family functioning (Barney & Max, 2002; Miller et al, 1985). Higher scores on subscales of the Family Assessment Device and in general family functioning are more problematic. A score of above 2 in general family functioning achieves 83% diagnostic accuracy (Miller et al, 1985). Cut-off scores are also suggested for individual subscales (Miller et al, 1985). Some scale items require reverse coding. Table 2.1 contains example items from each subscale of the Family Assessment Device.

**Table 2.1.** Example items from the Family Assessment Device (FAD)

FAD Subscale	Example Items
Problem Solving	'We usually act on our decisions regarding problems.'
	'We try to think of different ways to solve problems.'
Communication	'When we don't like what someone has done, we tell them.'
	'You can't tell how a person is feeling from what they are saying.'
Roles	' If people are asked to do something, they need reminding.'
	'We are generally dissatisfied with the family duties assigned to us.'
Affective	'We do not show our love for each other.'
Responsiveness	'We cry openly.'
Affective	'We show interest in each other only when we can get something
Involvement	out of it.'
	'We are too self-centred.'
Behaviour	'We don't hold to any rules or standards.'
Control	'We have rules about hitting people.'
General	'We confide in each other.'
Functioning	"There are lots of bad feelings in the family."

## 2.3.3.2 The FIT Profiler

The FIT Profiler (Fletcher, 1999) is an 83-item measure of personal strengths in thinking and behaviour. The FIT Profiler is comprised of two sections. In the first there are 75 questions with six subscales relating to each of the Constancies (Awareness, Self-responsibility, Fearlessness, Conscience and Balance), and Behavioural Flexibility. This section contains 10 items on each Constancy and 15 items measuring Behavioural Flexibility. Items are rated using single or multiple tick responses to indicate the degree to which a person possesses a cognitive or behavioural quality. Specific items pool together to comprise subscale scores in each of the Constancies and in Behavioural Flexibility. Higher scores on subscales of The FIT Profiler indicate greater personal strengths. Scores on subscales measuring the Constancies range from 1 to 10 and scores in Behavioural Flexibility range from 0 to 100. The FIT Profiler also includes a composite score for the Constancies called FIT Integrity, which ranges from 1 to 100.

The second section of The FIT Profiler contains 8 items on Thoughts and Feelings. Four of the items measure levels of depression and 4 items measure levels of anxiety. Participants read a list of symptoms and indicate the extent to which each item applied to them over the past few weeks. Responses are indicated using a 4-point scale ranging from 'never' to 'very frequently'. Scores in depression and anxiety range from 4 to 16, with higher scores being more problematic. The FIT Profiler has good internal consistency & test-retest reliability, and scores from the Thoughts and Feelings Scale correlate well with measures such as the Depression Anxiety Stress Scales- Short Form (Lovibond & Lovibond, 1995) and the Beck Depression Inventory (Beck, Steer & Brown, 1996) (Fletcher & Page, 2007). Fletcher and Page (2007) also report the psychometric properties of The FIT Profiler, showing that scales measuring the Constancies and Behavioural Flexibility have both adequate internal consistency and test-retest reliability. Example items from each of The FIT Profiler scales are shown in table 2.2. Figures 2.1 and 2.2 also display examples of response scales used for items in The FIT Profiler measuring the

Constancies (single tick response) and Behavioural Flexibility (multiple tick response).

**Table 2.2.** Example items from The FIT Profiler

FIT Profiler Subscale	Example Items
Awareness	'Do you find yourself daydreaming?'
	'Do you monitor/ analyse things you have done?'
Self-responsibility	'To what extent do you believe luck contributes to your
	success?'
	'To what extent do you take charge of your life?'
Conscience	'Do you think it is possible to be ethical/moral and successful?'
	'Do you think you have to lie to achieve success?'
Balance	'Do you believe it is important to develop a balance between
	work and home?'
	'When you are at work, is your mind on other things?'
Fearlessness	'Do feelings of insecurity make you fearful?'
	'Does entering new situations and meeting new people worry
	you?'
Behavioural Flexibility	'Do you behave in a conventional or unconventional manner?'
	'Are you an assertive or unassertive person?'
Depression	'Feeling low and wanting to give up trying.'
	'Feelings of sadness first thing in the morning.'
Anxiety	'Finding it difficult to think on the spot and concentrate.'
	'Feeling uneasy and needing to escape.'

Do you find yourself DAY DREAMING?	5 4 3	2 1 0 1	2 3 4 5
[SINGLE TICK ONLY]	Yes, always	Neither one nor the other	No, never
Figure 2.1. Example of a response scale	e for an item n	neasuring the Co	nstancy of
Awareness			
Do you behave in a CONVENTIONAL or UNCONVENTIONAL manner?	5 4 3	2 1 0 1	2 3 4 5
	Conventional	Neither one nor the other	Unconventional

**Figure 2.2.** Example of the response scale for an item measuring Behavioural Flexibility

# 2.3.3.3 The Family Habit Assessment Tool

In addition to assessing family functioning, the Family Assessment Device was used to measure family habits. This was achieved by adapting the general family functioning scale to include two habit scales, a frequency scale and an automaticity scale. Example items contained in table 2.1 show that the Family Assessment Device measures the patterns of interactions or behaviours within families. To intervene, it would be useful to know which behaviours families will benefit most from developing, and tackling. For example, some of the problems families experience will be less frequent than others. This level of detail on family behaviours might provide a guide as to where intervention might be most effective, at least in the short-term.

Drawing on Verplanken & Orbell's (2003) suggestion that habits should be measured as psychological constructs, two alternative scales were developed to include below each item of the general functioning scale. Participants were required to provide two additional responses for each of the 12 items included in the general functioning scale. The first response required participants to state the frequency with which an item applied to their family. The second response asked people to indicate how much thought was given to a behaviour in question. The two alternative scales were termed the Family Habit Assessment Tool (FHAT) and provide two composite scores- 'effective family habits' and 'ineffective family habits'. This is because the general functioning scale contains 6 positively worded and 6 negatively worded items. For positively worded items, scores across the 6 items for the two habit scales were summed and divided by 12 to provide a mean scale score. The same method was adopted to calculate an 'ineffective habit score' for the negatively worded items. High scores on the habit scales represent the presence of more family habits that are either effective or ineffective for family functioning. Raw scores on the habit scales range from 24 to 48. As the Family Assessment Device uses mean scale scores in assessing family functioning, the habit scales also used mean scale scores giving a scale range from 2 to 8 (from non habitual to highly habitual behaviour).

Traditionally, frequency of behavioural repetition is the most commonly employed measure of habit strength (Verplanken & Orbell, 2003). This is why a scale measuring frequency was developed. For each item on the general family functioning scale, participants rated how frequently the statement applied to their family on a scale ranging from 4 'all of the time' to 1 'never'. Automaticity is also relevant when measuring habits. It is commonly believed that habits are uncontrollable, automated responses that require little thought in guiding behaviour (e.g. see Wood et al, 2002; Verplanken & Aarts, 1999; Verplanken & Orbell, 2003). The second habit scale looked at how much thought was given to the behaviours measured by the general functioning scale. The automaticity scale ranged from 4 'no thought' to 1 'much thought and consideration'. An example of an

item from the general functioning scale with the new response formats is given in table 2.3. Scores on the habit scales were used to explore whether family habits are related to scores on FIT variables and in general family functioning.

 Table 2.3. Example item from The Family Habit Assessment Tool (FHAT)

Original FAD Item	Frequency Scale	Automaticity Scale
	This is true of us:	This is something we
		do or happens:
We can express	All of the time.	Without giving it any
feelings to each other		thought.
	Frequently.	With very little
		thought.
	Rarely.	With some thought.
	Never.	After much thought
		and consideration.

#### 2.4. Results

# 2.4.1 Descriptive statistics

Tables 2.4 and 2.5 present descriptive statistics and standard deviations (SD) for all variables measured within this study -from the Family Assessment Device (FAD), the Family Habit Assessment Tool (FHAT) and The FIT Profiler. Scale scores in each of the areas within tables 2.4 and 2.5 will be used to test the previously stated research hypotheses.

Data from the Family Assessment Device and the Family Habit Assessment Tool is presented in table 2.4. For individual scales of the Family Assessment Device, the suggested clinical cut-off scores by Miller et al (1985) are also given. There is also indication of the proportion of the sample scoring within the healthy or effective functioning range of each subscale.

The sample means in table 2.4 show that people in this study had somewhat negative perceptions of family functioning. High scores on subscales of the Family Assessment Device and in general functioning reflect the perception of more problems in family life. Mean scale scores in each area of the McMaster Model of Family Functioning are equal to or above the suggested clinical cut-off. The mean for the general family functioning scale was 2.02 (SD=0.55) where the clinical cut-off score is 2. A similar pattern of results was observed for other areas of family life. For example, the mean of the problem solving scale was 2.22 (SD=0.52) and the clinical cut-off is 2.2. There are consequently fewer people, given that this was a community sample, scoring in the healthy family functioning ranges of the subscales. Only 48.1% of the sample had an overall family functioning score in the healthy range. Affective involvement is the area in which most people's responses fell within the acceptable range (60.4% of participants scored in the healthy functioning range). Behaviour control was the most problematic area with only 46.8% of scale scores in the effective range.

Data from the Family Habit Assessment Tool on the other hand shows a relatively high number of effective family habits. The scale range of scores is between 2 and 8 where higher scores reflect more habitual behaviour. For effective family habits, the mean habit score was 6.20 (SD=0.95). The mean of the ineffective family habit scale was lower (M=4.77, SD=0.86).

**Table 2.4.** Mean (SD) scale scores for variables measured by the Family Assessment Device (FAD) and the Family Habit Assessment Tool (FHAT)

FAD/ FHAT Subscale	Mean scale score (N=235)	FAD cut-off score	Percentage scoring within the healthy range of the scale
FAD:			
Problem Solving	2.22(0.52)	2.2	57.2%
Communication	2.27(0.43)	2.2	56.6%
Roles	2.37(0.46)	2.3	57.9%
Affective Responsiveness	2.28(0.61)	2.2	50.6%
Affective Involvement	2.11(0.49)	2.1	60.4%
Behaviour Control	1.98(0.42)	1.9	46.8%
General Functioning	2.02(0.55)	2.0	48.1%
FHAT:			
Effective Family Habits	6.20(0.95)	-	-
Ineffective Family Habits	4.77(0.86)	-	-

Table 2.5. Mean (SD) scale scores for variables measured by The FIT Profiler

FIT Profiler Subscale	Mean scale score (N=235)
FIT Integrity	58.20 (9.40)
Awareness	6.18 (1.26)
Self-responsibility	6.02 (1.17)
Fearlessness	5.17 (1.06)
Conscience	6.81 (1.55)
Balance	4.90 (1.93)
Behavioural Flexibility	20.29 (15.67)
Depression	7.74 (2.91)
Anxiety	8.92 (3.08)

Data for the sample from The FIT Profiler is shown in table 2.5. This data relates to cognitive and behavioural strengths in areas of FIT Science. Scores in the Constancies range from 0 (low level of cognitive strengths) to 10 (high level of cognitive strengths). Behavioural Flexibility scores range from 0 to 100, with higher scores indicating more flexibility in behaviour. Table 2.5 shows that the sample consisted of people with a degree of personal strengths in the cognitive FIT variables called the Constancies. The sample mean was highest for Conscience (M=6.81, SD=1.55). This indicates strengths in behaving ethically and with moral integrity. Scores in the Constancy of Balance were below average given that each Constancy is scored out of 10 (M=4.90, SD=1.93). The Behavioural Flexibility score for the sample was also fairly low (M=20.29, SD=15.67).

Scores on the Thoughts and Feelings Scale of The FIT Profiler measuring levels of depression and anxiety were fairly low. The sample mean for depression was 7.74, (*SD*=2.91) and for anxiety the mean was 8.92 (*SD*=3.08). Stress scores range between 4 and 16 with higher scores equating to elevated levels of stress. For depression, 80% of the sample scored in the normal range, 13 people were experiencing marginal levels of depression and 16 people scored in the clinical range of the depression scale. Just over 72% of participants scored in the normal range for anxiety, 30 people scored in the marginal range and 35 people were experiencing clinical levels of anxiety.

# 2.4.2 Are FIT Science variables related to how people perceive their family functioning?

The first set of analyses present results from a series of Pearson's correlations that were carried out to explore the relationship between FIT variables and perceptions of family functioning. Based on past applications of FIT Science, it was hypothesized that individuals scoring high on FIT variables will report fewer problems in family functioning in areas measured by the Family Assessment Device. Low scores on the Family Assessment Device reflect fewer problems in family functioning. High scores on FIT variables indicate more personal strengths for coping. It was expected that there might be a negative correlation between scores on The FIT Profiler and scores on the Family Assessment Device. Table 2.6 shows the results of the correlations that were carried out.

Table 2.6. Results of Pearson's correlations between FIT Science variables and subscales of the Family Assessment Device (FAD)

FIT Profiler Scale	Problem	Communication	Roles	Affective	Affective	Behaviour	General
	Solving			Responsiveness	Involvement	Control	Functioning
FIT Integrity	20**	22**	14*	15**	19**	26**	28**
Awareness	14*	25**	08	08	14*	14*	26**
Self-responsibility	17**	18**	13*	18*	16**	27**	20**
Fearlessness	13*	10	16**	18**	12*	13*	24**
Conscience	17**	11*	02	12*	15*	29**	16**
Balance	01	15**	05	.07	07	01	04
Behavioural Flexibility	17**	13*	06	11*	14*	02	17**
Depression	.14*	.15**	.20**	.09	.15**	.08	.22**
Anxiety	.12*	.12*	.23**	.12*	.16**	.04	.27**

<sup>\*</sup> Correlation is significant at 0.05, one-tailed \*\* Correlation is significant at 0.01, one-tailed

Table 2.6 confirms the negative correlations that were predicted between FIT variables and perceptions of family functioning in areas measured by the Family Assessment Device. This suggests that people scoring high on FIT variables reported fewer problems in family functioning. FIT Integrity was consistently significantly related to how people perceived their family functioning in areas of the McMaster Model of Family Functioning. There was also a small to modest correlation between FIT Integrity and general family functioning (r(232) = -0.28, p < 0.001, one-tailed). A similar pattern of results was observed for perceptions of general family functioning and FIT Behavioural Flexibility (r(232) = -0.17, p < 0.01, one-tailed). There were also several significant correlations between the Constancies and dimensions of the Family Assessment Device. Non-significant correlations were also in the anticipated direction. The Constancy of Self-responsibility was the only Constancy that was significantly correlated with every dimension of family life. The correlation coefficients suggest that FIT variables and family functioning have a small to modest relationship in the anticipated direction. People who perceive their families to be more effective are characterized by greater personal strengths in the areas of FIT Science measured by The FIT Profiler.

#### 2.4.3 Are FIT variables related to personal stress?

Table 2.7 shows the results of Pearson's correlations that were carried out between FIT variables and scores on the Thoughts and Feelings Scale, which measures levels of depression and anxiety. The table shows that self-reported levels of depression are significantly correlated with strengths in each of the Constancies. A similar pattern of results emerges for correlations between the Constancies and anxiety scores, although the correlation between Conscience and anxiety failed to reach significance (r(232) = -0.9, p = 0.08, one-tailed). FIT Behavioural Flexibility was not significantly correlated with stress scores, although the correlation coefficients were in the anticipated direction. The results suggest that people scoring low on cognitive FIT variables experience higher levels of personal stress.

**Table 2.7.** Results of Pearson's correlations between FIT Science variables and scores on the Thoughts and Feelings Scale

	Depression	Anxiety
FIT Integrity	44**	44**
Awareness	25**	32**
Self-responsibility	39**	37**
Fearlessness	36**	40**
Conscience	13*	09
Balance	38**	30**
Behavioural Flexibility	05	05

<sup>\*</sup> Correlation is significant at 0.05, one-tailed

# 2.4.4 What is the relationship between family functioning, personal stress and FIT Science variables?

Table 2.6 shows several significant correlations between depression and anxiety scores and how people perceive their family functioning. The correlations show that as family functioning in areas of the McMaster Model of Family Functioning becomes more problematic, scores in depression and anxiety increase. Tables 2.6 and 2.7 also suggest that how people score on FIT variables is significantly related to perceptions of family functioning and self-reported levels of depression and anxiety.

Pearson's correlations between scores in individual areas of family functioning with each depression and anxiety scores were repeated partialling out the effect of FIT Integrity. This was with the aim of understanding the relationship between family functioning, personal stress and FIT variables. FIT Integrity was partialled out because data from this study and past research supports the role of cognitive strengths in how much personal stress people experience. The results of the correlations are shown in table 2.8.

<sup>\*\*</sup> Correlation is significant at 0.01, one-tailed

Table 2.8 shows that after controlling for FIT Integrity, the majority of correlations between scores on subscales of the Family Assessment Device with depression and anxiety scores are no longer significant. This is with exception to scores in the family area of roles. After controlling for FIT Integrity, perceptions of family functioning in this area remained significantly correlated with levels of both depression and anxiety. The correlation between general family functioning and anxiety also remained significant after controlling for the effect of FIT Integrity. Overall, the results suggest that FIT Integrity might mediate the relationship between aspects of family functioning and personal stress. This suggests that it is worth further exploring the role of personal strengths in how people cope with events relevant to the family.

**Table 2.8.** Results of Pearson's correlations between scores on the Family Assessment Device (FAD) and the Thoughts and Feelings Scale -controlling for FIT Integrity

FAD Scale	Depression	Controlling	Anxiety	Controlling
		for FIT		for FIT
		Integrity		Integrity
Problem Solving	.13*	.04	.11*	.02
Communication	.13*	.03	.10	.00
Roles	.18**	.13*	.22**	.16*
Affective Responsiveness	.09	.01	.11*	.05
Affective Involvement	.14*	.05	.15**	.07
Behaviour Control	.06	05	.03	10
General Family Functioning	.20**	.08	.26**	.15*

<sup>\*</sup> Correlation is significant at 0.05, two-tailed

<sup>\*\*</sup> Correlation is significant at 0.01, two-tailed

## 2.4.5 Are FIT variables predictive of family functioning?

A regression analysis was carried out to further investigate whether FIT variables are predictive of general family functioning. Table 2.6 shows several significant correlations between FIT variables and how people perceive their family functioning in areas of the McMaster Model. A regression analysis was carried out to find out the amount of variability in perceptions of overall family functioning that is attributed to the personal strengths of individuals.

Since table 2.6 shows several significant correlations between the Constancies and overall family functioning, FIT Integrity, a composite score, was entered into the regression model. FIT Behavioural Flexibility was also entered in the model. Table 2.6 shows that Behavioural Flexibility is also significantly associated with how people perceive their overall family functioning. The regression analysis was carried out using the stepwise method to understand what each variable added to explaining perceptions of family functioning. The results of the regression analysis are shown in table 2.9.

The results show that both FIT Integrity and Behavioural Flexibility are predictive of how people perceive their family functioning. The beta coefficients show that FIT variables have a protective effect on family functioning. Step one of the regression analysis including only FIT Integrity showed this to account for 8.8% of variability in how people perceive their family functioning. Behavioural Flexibility accounted for a further 3.4% of variability, with the final model including FIT Integrity and Behavioural Flexibility accounting for 12.2% of variability in how people perceive their family functioning.

**Table 2.9.** Coefficients of the regression predicting general family functioning

Model Predictors	Unstandardized Coefficients	t	Significance
Step 1			
Constant	3.05		
FIT Integrity	02	-4.74	.001**
Step 2			
Constant	3.13		
FIT Integrity	02	-4.50	.001**
Behavioural Flexibility	01	-3.00	.01*

<sup>\*</sup> Significant at p < 0.05, one-tailed

# 2.4.6 What is the relationship between FIT variables and family habits?

The final analyses investigated the relationship between FIT variables and family habits. It was expected that people scoring high on FIT variables might report more effective family habits and fewer ineffective family habits. Before testing these associations, it was necessary to first explore the relationship between how people scored in general family functioning and scores on the family habit scales. This is because the family habit scales were based on the general family functioning scale from the Family Assessment Device. It was therefore important to explore the conceptual appropriateness of treating the habit scales as distinct to the general functioning scale. It was expected that the family habit scales might be correlated with scores in general functioning such that people reporting more problems in family functioning might report more ineffective family habits and fewer effective family habits. For the scales to be treated as distinct, the correlations would nonetheless need to be small to moderate.

Table 2.10 presents the results of Pearson's correlations that were carried out between scores on the effective and ineffective family habit scales, scores on the general family functioning scale from the Family Assessment Device and variables measured by The FIT Profiler. Table 2.10 shows that there was a moderate negative correlation between scores on the general family functioning scale with effective family habits (r(148) = -0.71, p < 0.01, one-tailed). This suggests that people

<sup>\*\*</sup> Significant at p < 0.01, one tailed

reporting more problems in general family functioning perceived their families to be characterized by fewer habits that support family functioning. Ineffective family habits were not significantly correlated with general family functioning (r(148) =. 10, p =. 10, one-tailed), although the correlation coefficient was in the anticipated direction. This suggests that family functioning might be strongly associated with the nature of effective family behaviours and not necessarily the number of problems a family faces. The results also suggest that the scales forming the Family Habit Assessment Tool do not correlate highly with scores on the general functioning scale. This indicates that participants treat the scales differently and so the frequency and automaticity scales are likely to measure something different to the general family functioning scale i.e. family habits and not agreement with scale items.

Table 2.10 also shows several correlations between the family habit scales and scores on FIT variables. The results suggest that FIT variables are significantly associated with the habit scales in the anticipated direction. FIT Integrity and the Constancies (excluding Balance) were consistently related to effective habits, where the association between personal strengths and ineffective family habits failed to reach significance, other than for overall FIT Integrity. The correlation coefficients were however in the expected direction. An interesting finding was that Behavioural Flexibility was positively correlated with ineffective family habits (r(148) = 0.19, p < 0.01, one-tailed). Taken together the results suggest that FIT variables are associated with the types of behaviors people use or develop to deal with issues relevant to the family, specifically behaviours that are beneficial for the family. People scoring high on cognitive FIT variables report more effective family habits.

**Table 2.10.** Pearson's correlations between measures from the Family Habit Assessment Tool (FHAT), the Family Assessment Device (FAD) and The FIT Profiler

	Effective Family Habits	Ineffective Family Habits
FAD:		·
General Functioning	71**	.10
FIT Profiler:		
FIT Integrity	.34**	19**
Awareness	.28**	12
Self-responsibility	.18*	09
Fearlessness	.35**	20
Conscience	.14*	09
Balance	.08	09
Behavioural Flexibility	.05	.19**
FHAT:		
<b>Effective Family Habits</b>	-	16*

<sup>\*</sup> Correlation is significant at 0.05, one-tailed \*\* Correlation is significant at 0.01, one-tailed

#### 2.5. Discussion

The aim of this study was to undertake the first empirical investigation of the relationship between FIT Science variables and how people perceive their family functioning. Research using FIT Science suggests that people who score high on FIT variables cope better with different areas of life. Fletcher and Stead (2000) suggest this includes issues relevant to social domains. Because of a range of individual cognitive and behavioural strengths, people scoring high on FIT Integrity, the Constancies and Behavioural Flexibility, were expected to report fewer problems in areas of the McMaster Model of Family Functioning. The study also explored whether FIT variables significantly account for differences in how people perceive the overall health of the family. Furthermore, the study was the first to explore the relationship between how people score on FIT variables and the types of habits present in family life. A final aim of the study was to explore whether FIT variables mediate the relationship between personal stress and perceptions of family functioning. In doing so, the study tested the proposed relationship between FIT variables and levels of personal stress reported elsewhere (e.g. see Hanson, 2008).

# 2.5.1 FIT Science and family functioning

The study provided evidence suggesting that FIT variables are related to how people perceive their family functioning. There were several significant negative correlations observed between FIT variables and scores on subscales of the Family Assessment Device, which measures family health across the areas of the McMaster Model of Family Functioning. This indicates that people scoring high on FIT variables report fewer problems in family functioning. For correlations that failed to reach significance, the correlation coefficients were in the anticipated direction. In addition, FIT Integrity (a composite score of the Constancies) and Behavioural Flexibility, significantly predicted just over 12% of variability in how people perceive their general family functioning. Specifically, the variables had a protective effect on perceptions of family life.

Family functioning is a multi-dimensional construct (McCreary & Dancy, 2004), which is likely to be affected by a number of different factors including things such as the family's eco-context (social economic status, urban or rural location etc) (Schneewind, 1989). The finding here that FIT variables predict how people view their general family functioning is important because it delineates the many factors that might contribute to the family functioning context. It also highlights the difficulty in taking a limited approach in studying the family since each family member has their own construction of family strengths and difficulties. This study suggests that personal resources for coping, such as those measured by The FIT Profiler, help explain variations in how people perceive their circumstances. The research supports principles of FIT Science, finding that because of personal resources for coping, people scoring high on FIT variables experience fewer problems in social domains. Systems models of family functioning tend to underestimate the role of the individual in family experiences. This study suggests that future research should consider how factors intrinsic to family members influence how they attempt to cope with and are subsequently affected by family events.

#### 2.5.2 Family functioning, personal stress and FIT variables

The association between family functioning and psychological stress is well established in the research literature and was also supported in this study. The study consistently found that problems in areas of the McMaster Model of Family Functioning were associated with higher levels of both depression and anxiety. People perceiving more problems in family functioning reported higher levels of depression and anxiety.

The study also supported the findings of Fletcher (2007b) and Hanson (2008) showing that FIT variables are associated with levels of personal stress. The study demonstrated that people scoring high on FIT variables experience lower levels of depression and anxiety. The study also showed that for several areas of family functioning, personal resources for coping mediated the relationship between

functioning and stress. Correlations between scores in areas of the Family Assessment Device with personal stress scores were carried out controlling for the effect of FIT Integrity. Consequently, in the main, significant associations between family functioning and stress were no longer statistically supported. This is strong evidence to suggest that the personal strengths measured by The FIT Profiler are relevant to understanding how people experience the family. The findings suggest that because of their coping abilities, people scoring high on FIT variables show resilience towards problems in the family and subsequently experience less stress. Cowan, Cowan and Schulz (1996) describe resilience as 'some individuals and families possess physiological strengths, psychological resourcefulness and interpersonal skills that enable them to respond successfully to major challenges and to grow from the experience' (pp. 14-15). This description of resilience fits very well with Fletcher & Stead's (2000) explanation of the characteristics of the FIT individual 'Essentially a FIT person can FIT themselves to the demands of the situation. They will be healthier, more satisfied, more able to cope with all situations, and more productive...FITness allows people to jettison their bad personal baggage, including poor or inappropriate learning and to develop individual talents to maximum advantage' (p. 13).

The role of FIT variables in developing resilience and protecting people from psychological distress has several implications for interventions. Specifically, promoting personal strengths for coping using interventions targeted at developing FIT thinking and behaviour are predicted to lead to better perceptions of family functioning and lower levels of stress. This might reflect actual change in the ability of individuals to cope with the family environment.

#### 2.5.3 Family habits and FIT variables

The Family Assessment Device as an instrument itself raised an important issue. Items comprising the general functioning scale measure the behaviours or patterns of interactions within families. However, the response scale of the instrument measures agreement with scale items. This provides limited insight into the nature of day-to-day family behaviours. It was anticipated that a person might endorse an item on the general functioning scale but this does not provide insight into how much of a problem or strength of a family is being indicted because other items will also have been endorsed. For example, a person who strongly agrees that in their family, it is difficult to plan family activities may genuinely believe this is a family problem. However, this does not say anything about how often the family members actually try and plan family activities. This may, for example, only be a yearly occurrence referring to family holidays but nonetheless represent a true family problem. Other items, which have been endorsed, might however reflect problems presenting themselves frequently such as not being able to communicate openly with family members.

In this study, the concept of habit was drawn on to develop two scales from which it was possible to derive a measure of effective and ineffective family habits. In a clinical context, these scales might allow for exploring the effective behaviours in families that are carried out frequently and unconsciously that support the functioning of the system. More importantly, it might also allow clinicians to use responses on the scales to see which family behaviours are useful and endorsed but still require support in maintenance and also those that are frequently occurring, entrenched patterns of behaviour that need tackling.

The study found that scores on the habit scales showed small to moderate correlations with general functioning. This supports the conceptual relevance of the habits scales, suggesting they measure something distinct to agreement with items on the Family Assessment Device. Additionally, the study found that effective habit scores were significantly related to perceptions of general family functioning, but

the same was not true for ineffective family habits. This indicates, as other researcher have found, that family functioning is determined by marked positive features over the problems families contend with (Westley and Epstein, 1969).

The study also found that key aspects of FIT Integrity were significantly related to the presence of effective family habits. Overall, FIT Integrity, and not the individual Constancies, were however related as anticipated to ineffective family habits. This suggests that there might be a close relationship between 'FITness' and appropriate behaviour in different situations such as those involving the family. The association between ineffective habits and cognitive FIT variables requires further investigation.

## 2.5.4 Strengths and limitations

This study was the first to undertake the empirical examination of the relationship between FIT variables and family functioning, although Fletcher and Stead (2000) and Hanson (2008) have suggested that FIT variables might be relevant for outcomes related to social domains. This research therefore advances knowledge of both family functioning, and how FIT variables relate to individual perceptions across a range of different situations. The research reported here has also highlighted several areas for further investigation, including the role of interventions developing personal strengths in protecting the family environment and the psychological well being of individuals. The study was also the first to attempt the measurement of family habits and shed light on the nature of family behaviours that shape functioning.

The study is not without limitations. The data collected on family functioning was self-report, including only the perceptions of individual family members. Systems models of family functioning call for the inclusion of the perspective of all family members when assessing the health of the system. Whilst this approach can be useful, this study addressed how the characteristics of individuals relate to their personal constructions of family life. Subjective accounts of family functioning are

not expected to change the results for the study in any way. The habit scales developed would also have benefit from assessment of test-retest reliability and looking at internal consistency of responses. The wider use of the scales is therefore limited. Finally, data from the Family Assessment Device shows that a high proportion of scores in the areas of the McMaster Model fell within Miller et al's (1985) clinical range. For example, Miller et al reported 22% of non-clinical families and 59% of clinical families falling within the unhealthy functioning range of the general family functioning scale. This study recruited both a general population and student sample, finding just over 51% of scores in general functioning falling in the scales clinical range. This suggests more problems in family functioning than expected in a general population sample. On the other hand, there is no reason to believe that this sample is in any way clinical, especially as scores on the Thoughts and Feelings Scale of The FIT Profiler were generally low. For example, the depression scores of 16 out of 235 participants fell in the clinical range. The majority of scores (of 188 people) were in the normal range. A similar pattern of results emerged for anxiety. From the data available, it is therefore unclear why scores on the Family Assessment Device were high for the study sample. One suggestion is the sensitivity and specificity of the cut-off scores, which may need to be investigated further. An alternative, and perhaps more plausible explanation is that the sample was self-selecting. It may be that those who volunteered to take part in the study did so because of their family situation.

### 2.5.5 Conclusions

This study advances knowledge of family functioning by showing that characteristics of people play an important role in how they perceive family problems and functioning. Furthermore, the study suggests that the family environment does not have a deterministic effect on a person's level of stress. The implications of the findings are that models advanced to understand family functioning should consider the resources for coping that individuals bring to the family. By understanding these strengths, knowledge of facilitating resilience in families will also be promoted. Furthermore, the study suggests that measures such

as the Family Assessment Device can be adapted to provide information on the nature of family habits, which might prove useful in clinical contexts to facilitate intervening with family functioning.

## Chapter 3

Study two: The relationship between FIT Science variables and family functioning from the perspective of adults with Autistic Spectrum Conditions

### 3.1. Introduction

The previous study demonstrated that FIT variables are related to and predict how people perceive their family functioning. The study also demonstrated that FIT variables mediate the relationship between aspects of family life and personal stress. The finding that characteristics of people may protect them from problematic outcomes has several implications for intervening with family functioning. However, the vast majority of studies exploring how perceptions of family functioning are related to outcomes for individuals have been carried out with members from families facing unique challenges. This includes coping with chronic health conditions (e.g. Kazak & Drotar, 1997) and developmental conditions such as autism (e.g. Sander & Morgan, 1997). It is plausible that in these units, stressors within the environment might supersede the role of a person's own resources for coping.

This chapter explores whether FIT variables are useful for understanding family functioning in diverse contexts. The study explores whether the perceptions of family functioning of adults with High Functioning Autism and Asperger syndrome (a milder form of autism) (referred to as individuals with Autistic Spectrum Conditions or ASCs; Drew et al, 2002) are related to scores on FIT variables. Family functioning is likely to be compromised when a family member is affected by an ASC. Therefore, the individual affected by an ASC has the challenge of managing their own condition and may also be faced by additional problems in the family environment. This research investigates the extent to which FIT Science offers a framework from which to understand family functioning in potentially challenging contexts.

## 3.2. Autism: The condition and its impact on the family

## 3.2.1 Autistic Spectrum Conditions

Autism is a lifelong neurodevelopmental condition affecting approximately 1 in 100 individuals within the United Kingdom (UK) (National Autistic Society, 2010). It is a spectrum condition where those affected differ in ability but are generally characterized by a triad of impairment (Wing & Gould, 1979). This is reflected in the Diagnostic and Statistical Manual of Mental Disorders 4th edition as (1) qualitative impairments in reciprocal social interaction (2) verbal and non-verbal communicative difficulties and (3) restricted, repetitive and stereotyped behaviours and interests. Individuals with ASCs face many challenges over their lifetime. A study by Barnard, Harvey, Potter and Prior (2001) looking at adult outcomes of those affected by ASCs surveyed 458 members of the UK National Autistic Society (including parents and adults affected by ASCs). The study found that 49% of adults with ASCs lived with their parents, and many adults required a lot of help with tasks such as preparing a meal (50%), managing money (56%), shopping (42%) and personal care (31%). Furthermore, only 10% of adults with ASCs were in full or part-time employment and 80% of adults with ASCs reported family as the most important people in their lives due to them being unable to develop other meaningful relationships. Barnard et al's (2001) findings demonstrate how day-today life can be very challenging for those affected by ASCs. Research has also shown that both children and adults are at high risk of experiencing psychological distress, with anxiety and depression being common comorbidities. Simonoff et al (2008) found that 70% of children and adolescents with ASCs have at least one comorbid psychiatric condition and a further 41% experience more than one psychiatric comorbidity. Children and adults affected by ASCs therefore contend with many challenges over their life cycle.

## 3.2.2 Autistic Spectrum Conditions and the family

Research into ASCs and family life has consistently reported on the negative impact of ASCs on parents and the wider family. Early on, Holroyd and McArthur (1976) demonstrated that parents of children with ASCs report more problems in the family environment than parents of children with other disabilities including Down syndrome and psychiatric conditions. This suggests that ASCs pose a specific challenge for families. Subsequent research confirms a particular profile of stress in parents related to the nature of ASCs and associated problems in independent living and life-time care, cognitive functioning, and limits on family activity (Koegel et al, 1992). Schopler and Mesibov (1984) also recognized that stress in families of older children is greater. This is because families realize the permanency of impairments. Parents of younger children may believe that some characteristics such as problems in language development are overcome with age. Consequently, Schopler and Mesibov (1984) found that two thirds of parents worried about what would happen to their children when they were no longer able to care for them. In light of the characteristics of ASCs and the chronic nature of the condition, psychological distress and problems in family functioning are commonly reported in the literature on families with a member with an ASC (e.g. see Bouma & Schweitzer, 1990; Bromley, Hare, Davison & Emerson, 2004; Herring et al, 2006).

### 3.2.3 The impact of the family on the course of Autistic Spectrum Conditions

Morgan (1988) stated that whilst ASCs influences the family, the nature of the family environment itself influences the developmental course of the condition. Siller and Sigman (2002) for example showed that parent interaction with a young child with an ASC influences subsequent communicative development. Surprisingly, there have been very few studies looking at the bidirectional relationship between child influences on the family and the family influence on the child in the context of ASCs. More generally, reviews of psychological outcomes of young children with chronic health conditions have shown that the family indeed influences the course of disability (e.g. Pless & Nolan, 1991). For example, family cohesion is linked to positive outcomes, whereas families experiencing high levels of conflict usually

show worse psychological outcomes for children with chronic conditions (Kazak & Drotar, 1997). Hurlbutt and Charlmers (2002) also carried out interviews to explore the experiences of three adults with ASCS and found that the family was seen as very important to help those affected learn skills and develop personally. The lack of research into how adults with ASCs experience family life makes it difficult to understand how they are affected by the family in detail. Research has focused predominantly on the negative impact of people with ASCs on the family and failed to fully explore the association between family functioning and personal outcomes from the perspective of people affected by an ASC.

## 3.2.4 Adults with Autistic Spectrum Conditions and FIT Science variables

For adults with ASCs, it was hypothesized that FIT variables might be very important to perceptions of the family, and also to personal outcomes. This is because people affected by ASCs are inherently inflexible in their thinking and behaviour. Flexibility in thinking and behaviour are core features of the personal strengths identified by FIT Science, suggesting that adults with ASCs may be more likely to score low on FIT variables. Results from study one suggest that scoring low on FIT variables may be related to perceiving a person's family as experiencing more problems in functioning well, and also relates to reporting higher levels of depression and anxiety. Adults with ASCs might therefore be more prone to reporting problems in family functioning that might be mediated by a lack of cognitive and behavioural flexibility.

Typically, lack of behavioural flexibility in individuals affected by ASCs has been explored in the context of repetitive behaviours including rituals, insistence on sameness, compulsions, obsessions, self-injurious behaviour, tics, echolalia and circumscribed interests (e.g. see Bodfish, Symons, Parker & Lewis, 2000; Lewis & Bodfish, 1998). Repetitive behaviours in ASCs are often related to restricted cognitive flexibility and failure to inhibit responses, which are features of executive functioning (Turner, 1999). One avenue of research has therefore explored the ability of those affected on tasks drawing on executive functions such as the

Wisconsin Card Sorting Test (Heaton, 1981). Compared with both controls and clinically matched subjects (e.g. people with Tourette syndrome), individuals with ASCs consistently perform poorly on tasks drawing on executive abilities (Kleinhans, Akshoomoff & Delis, 2005; Ozonoff, Pennington & Rogers, 1991). This is specifically thought to be due to difficulty in inhibiting responses and shifting cognitive set (see Ozonoff & McEvoy, 1994).

It is proposed that the restricted and repetitive cognitions and behaviours of higher functioning individuals with ASCs may also be reflected in their thinking towards and behaviours selected to resolve day-to-day events. Adults with ASCs may score low on FIT variables when compared to controls. This might have implications for their personal outcomes (e.g. see Hanson, 2008) and perceptions of family functioning, as demonstrated in study one. FIT Science might offer a more practical approach to profiling the cognitive and behavioural characteristics of people affected by ASCs and understanding how this relates to perceptions of personal and family outcomes.

# 3.3. The Study

This study was carried out to explore the perspectives of adults with High Functioning Autism and Asperger syndrome on the functioning of their families. Many studies have demonstrated the negative impact of family variables on the outcomes of members but few have looked at how people with ASCs perceive their family functioning and explored variables that mediate experiences of the family. This study explored the association between family functioning in areas of the McMaster Model and the experience of personal stress from the perspective of adults affected by ASCs. More importantly, the study also explored the relationship between how adults with ASCs score on FIT variables, perceptions of family functioning, family habits and personal stress. The study aimed to answer the following questions:

- 1. How do adults with ASCs perceive their family functioning?
- 2. What is the relationship between family functioning and the experience of personal stress?
- 3. Are the scores of adults with ASCs on FIT variables related to perceptions of family functioning?
- 4. What is the relationship between family functioning, personal stress and FIT variables for adults with ASCs?
- 5. What is the relationship between family functioning and family habits from the perspective of adults with ASCs?

## 3.3.1 Hypotheses

Based on the research reviewed above and the findings of study one, the study has five specific hypotheses:

- 1. A high proportion of adults with ASCs will perceive their families as functioning ineffectively, as measured by the McMaster Family Assessment Device. Past research has consistently documented problems in family life from the perspective of parents of children with ASCs. It is anticipated that the perceptions of those affected will also mirror this finding.
- 2. FIT Science variables are expected to be associated with how adults with ASCs perceive their family functioning. The nature of ASCs and the findings of study one suggest that people scoring low on FIT variables are likely to report more problems in areas of the McMaster Model.
- 3. Perceptions of family life are expected to be related to personal stress, as measured by the Thought and Feelings Scale of The FIT Profiler. Research suggests that family variables impact psychological outcomes in chronic conditions. The study therefore expects to find a positive correlation between scores on the Family Assessment Device and the Thoughts and Feeling Scale.
- 4. 4. FIT Science variables are anticipated to mediate the impact of family life on personal stress. It is expected that adults with ASCs who are more flexible in

- their thinking and behaviour will be less personally affected by problems in the family.
- 5. It is expected that FIT variables will be related to the types of habits adults with ASCs report in family life. Adults with ASCs scoring high on FIT variables are expected to report more effective and fewer ineffective habits in their families.

### 3.4. Method

### 3.4.1 Participants

Fifty-two adults with ASCs (High Functioning Autism and Asperger syndrome) (25 males and 27 females) took part in this study. Participants ranged in age from 18 to 60 years, with the majority aged 41-50 (28.8%) and 22-30 years of age (23.1%). Just over 90% of participants described their ethnic origin as White-British. All participants were living with their families and predominantly reported their family structure as nuclear (59.6%). Just over 13 % of participants also reported their family structure as extended, and reconstituted, 5.8% were in a single-parent family and finally, 4 participants did not report on the structure of their family. To allow selected comparisons of adults with ASCs with controls, a comparison group was drawn from the participants from study one. Participants were matched on age, sex, ethnicity and family structure.

### 3.4.2 Procedure

This was questionnaire study. Participants were recruited via a research advertisement placed on the website of the National Autistic Society and through an advertisement in the Asperger United magazine (also published by the National Autistic Society). Those interested in taking part in the study contacted the researcher via post, email or telephone and were subsequently mailed the study materials and a self-addressed envelope. The study had a 71% response rate.

# 3.4.3 Questionnaire Measures

The questionnaire pack completed by participants consisted of four sections. The first section asked various demographic questions including participants age, sex and family structure. The questionnaire pack also contained a section with the Family Assessment Device (FAD), The FIT Profiler, and the Family Habit Assessment Tool (FHAT). Details on each of the respective measures can be found in the method section of study one.

## 3.5. Results

## 3.5.1 Descriptive Statistics

Tables 3.1 and 3.2 present descriptive statistics and standard deviations (SD) for all variables measured within this study -from the Family Assessment Device (FAD), the Family Habit Assessment Tool (FHAT) and The FIT Profiler. Scale scores in each of the areas within tables 3.1 and 3.2 will be used to test the previously stated research hypotheses.

Data from the Family Assessment Device and the Family Habit Assessment Tool is presented in table 3.1. For individual scales of the Family Assessment Device, suggested clinical cut-off scores by Miller et al (1985) are also given. Table 3.1 also includes alternative cut-off scores proposed by Miller et al (1985) that achieve higher diagnostic accuracy. Applying both types of scores, indication is given of the proportion of sample scores in the healthy functioning ranges. Miller et al (1985) also reported data on the number of families with a psychiatric member that score within the healthy ranges of the Family Assessment Device. This data has been included in the table as a comparison. Higher scores in areas of the Family Assessment Device are more problematic.

The sample means in table 3.1 suggest that adults with ASCs had very negative perceptions of family functioning. Mean scale scores in each area of the McMaster Model of Family Functioning are above the suggested clinical cut-offs. The mean for the general family functioning scales was 2.51 (*SD*=0.65) where the clinical cut-off score is 2. When the alternative cut-off scores were applied, the majority of mean scale scores remained above the cut-off score. For example, the alternative cut-off score for the general functioning scale is 2.2 and so the sample mean of 2.51 remains above the suggested threshold. Looking at the percentage of scale scores in the healthy range when applying both cut-off scores, communication is consistently the family area with least scores within the healthy range. With the alternative cut-off score, only 26.9% of the sample perceived their families as functioning well in

this area. Behaviour control was consistently the area seeing most scores within the healthy range.

Comparing the proportion of the ASC sample reporting healthy perceptions of family functioning with data from a psychiatric sample, it seems that families with a member affected by an ASC experience more problems in functioning well. Just over 40% of Miller et al's (1985) psychiatric sample reported healthy perceptions of general family functioning. This compares to only 21.2% in the ASC sample reported here. A similar pattern of results is seen across other areas of the McMaster Model.

Data from the Family Habit Assessment Tool on the other hand shows a relatively high number of effective family habits with a mean score of 5.15 (SD=1.36). Scores on the habit scales range from 2 to 8, with higher scores indicating more habitual family behaviours. Adults with ASCs however reported marginally more ineffective habits in family life (M=5.19, SD=1.24).

**Table 3.1.** Mean (SD) scale scores of adults with ASCs from the Family Assessment Device (FAD) and the Family Habit Assessment Tool (FHAT)

FAD/ FHAT Subscale	Mean scale score (N=52)	FAD cut-off score	Percentage scoring within the healthy range of the scale (N=52)	Psychiatric sample scoring in the healthy range of the scale*	FAD cut-off score (alternative)	Percentage scoring within the healthy range of the scale (N=52)
FAD:						
Problem Solving	2.53 (0.60)	2.2	21.2%	44%	2.3	40.4%
Communication	2.49 (0.45)	2.2	13.5%	31.7%	2.3	26.9%
Roles	2.51 (0.44)	2.3	23.1%	51.2%	2.4	48.1%
Affective Responsiveness	2.71 (0.65)	2.2	19.2%	46.3%	2.4	34.6%
Affective Involvement	2.36 (0.57)	2.1	30.8%	39%	2.4	55.8%
Behaviour Control	2.08 (0.57)	1.9	48.1%	53.7%	2.1	59.6%
General Functioning <i>FHAT:</i>	2.51 (0.65)	2.0	21.2%	41%	2.2	36.5%
Effective Family Habits	5.15 (1.36)	-	-	-	-	-
Ineffective Family Habits	5.19 (1.24)	-	-	-	-	-

<sup>\*</sup> Data from Miller et al (1985)

Table 3.2. Mean (SD) scale scores for adults with ASCs from The FIT Profiler

FIT Profiler Subscale	Mean scale score (N=52)	Mean scale score of normative comparison group from study 1 (N=52)
FIT Integrity	49.15 (9.44)	59.83 (8.23)
Awareness	4.98 (1.30)	6.20 (0.94)
Self-responsibility	4.89 1.56)	6.52 (1.00)
Fearlessness	2.70 (1.61)	4.95 (1.60)
Conscience	6.88 (1.56)	6.93 (1.40)
Balance	5.13 (0.95)	5.32 (1.03)
Behavioural Flexibility	18.17 (15.81)	21.73 (17.03)
Depression	9.46 (3.30)	6.69 (2.52)
Anxiety	10.61 (3.39)	7.50 (2.98)

Data for the ASC sample from The FIT Profiler is shown in table 3.2. This data relates to cognitive and behavioural strengths in areas of FIT Science. Scores in the Constancies range from 0 (low levels of cognitive strengths) to 10 (high levels of cognitive strengths). Behavioural Flexibility scores range from 0 to 100, with higher scores indicating more flexibility in behaviour. Table 3.1 shows that the ASC sample consisted of people with some personal strengths in the cognitive FIT variables called the Constancies. The sample mean was highest for Conscience (M=6.88, *SD*=1.56). This indicates strengths in behaving ethically and with moral integrity. Scores in the Constancy of Balance also indicated ability in the sample to pay due attention to different areas of life (M=5.13, SD=0.95). The sample scores in other areas of the Constancies seem to reflect the cognitive inflexibility of people affected by ASCs. Scores in Awareness, Self-responsibility and Fearlessness were below 5, indicating poor flexibility. Fearlessness was particularly low in the ASC sample with a sample mean score of 2.70 (SD=1.61) and this may mirror the close link between this Constancy and anxiety, which is commonly reported in people with ASCs. The Behavioural Flexibility score for the sample was also low (*M*=18.17, *SD*=15.81).

The sample mean for depression, as measured by the Thoughts and Feelings Scale of The FIT Profiler, was 9.46 (SD=3.30) and for anxiety the mean was 10.61 (SD=3.39). Stress scores range between 4 and 16, showing that the group means are generally low, although just over 38% of the sample scored in the marginal to clinical range for depression and 50% of anxiety scores were also in this range.

These scores were compared with the data from 52 participants in study one (see table 3.2). It is apparent from these comparisons that inflexibility in thinking and behaviour reported in the literature on ASCs is mirrored to some extent in scores on FIT variables. The ASC sample scored lower than the normative sample on all FIT variables. The ASC group also reported higher levels of personal stress. Independent samples t-tests were carried out to explore whether the observed differences in scores on FIT variables were statistically significant. The results of the t-tests showed that adults with ASCs, compared to a matched control group, scored low on FIT Integrity (t(102) = -5.69, p < 0.001, two-tailed), Awareness (t(102) = -4.71, p < 0.001, two-tailed), Self-responsibility (t(86.79) = -5.98, p < 0.001, two-tailed) and Fearlessness (t(102) = -6.87, p < 0.001, two-tailed). Adults with ASCs also reported significantly higher levels of depression (t(95.54) = 4.80, p < 0.001, two-tailed) and anxiety (t(102) = 4.98, p < 0.001, two-tailed).

# 3.5.2 Are FIT Science variables related to how adults with ASCs perceive their family functioning?

The descriptive data reported in section 3.5.1 suggests that adults with ASCs perceive their families as experiencing problems in functioning well. The first set of analyses were carried out to understand whether FIT variables are related to perceptions of family life. This has important implications for strengthening families and protecting individuals from problematic outcomes. A series of Pearson's correlations were carried out to explore the relationship between scores on FIT variables and how adults with ASCs experience the family. Based on the findings of study one, it was hypothesized that adults with ASCs scoring high on FIT variables

are likely to perceive their families as experiencing fewer problems in functioning effectively. Table 3.3 shows the results of the correlations that were carried out.

Table 3.3 shows several significant correlations between FIT variables and how adults with ASCs perceive their family functioning in areas of the McMaster Model. The correlations are negative, suggesting that people scoring high on FIT variables report fewer problems in family life. The area of behaviour control was not significantly associated with how people scored on FIT variables, although the correlation co-efficients were generally in the anticipated direction.

Table 3.3. Results of Pearson's correlations for adults with ASCs between FIT Science variables and subscales of the Family Assessment Device (FAD)

FIT Profiler Scale	Problem	Communication	Roles	Affective	Affective	Behaviour	General
	Solving			Responsiveness	Involvement	Control	Functioning
FIT Integrity	29*	23	54**	41**	34**	.15	27
Awareness	27*	33	37**	26*	41**	.07	36**
Self-responsibility	29*	25*	49**	37**	23	06	21
Fearlessness	22	26*	46**	44**	42**	21	27*
Conscience	13	.08	17	11	01	18	.09
Balance	03	.03	33**	13	02	11	.04
Behavioural Flexibility	.14	.14	.32*	.09	.15	.19	.14
Depression	.38**	.32*	.39**	.52**	.36**	.06	.37**
Anxiety	.28*	.29*	.39**	.46**	.37**	13	.38**

<sup>\*</sup> Correlation is significant at 0.05, one-tailed \*\* Correlation is significant at 0.01, one-tailed

To further explore the association between FIT variables and perceptions of family functioning, two independent samples t-tests were carried out. The t-tests explored differences in scores on FIT Integrity and Behavioural Flexibility between adults who scored in the healthy versus unhealthy range of the general functioning scale. For this analysis, FIT Integrity and Behavioural Flexibility were treated as dependent variables and the grouping variable was categorical- healthy or unhealthy family functioning score. Only 11 participants had general functioning scores falling within the healthy range of the scale and the scores of 41 participants were in the unhealthy range. The mean FIT Integrity score for the healthy functioning group was 54.61(SD=6.84), which was higher than that of people perceiving their general family functioning as problematic (M=48.23, SD=10.39). An independent samples t-test confirmed that adults who perceived their family functioning as healthy scored significantly higher on FIT Integrity (t(50)=1.92, p = 0.03, one tailed). Participants reporting healthy family functioning did not however differ significantly in levels of Behavioural Flexibility from those reporting unhealthy family functioning (t(50) = -.27, p = 0.39, one tailed). Together with the correlations reported in table 3.3 this suggests that the personal strengths of adults with ASCs, particularly in cognitive FIT variables, are related to perceptions of family functioning.

# 3.5.3 What is the relationship between family functioning, personal stress and FIT Science variables?

Table 3.3 shows that levels of depression and anxiety are significantly positively correlated with problems in the areas of the McMaster Model of Family Functioning. This suggests that adults with ASCs reporting more problems in family functioning experience higher levels of depression and anxiety. This is consistent with past research into the negative effect of family variables on outcomes in chronic conditions. Results from study one, and the broader application of FIT Science has shown that stress is also intimately related to the personal strengths of individuals. Study one demonstrated that the impact of aspects of family life on psychological

well being is in fact mediated by the personal strengths of individuals. The next set of analyses explored whether personal strengths, measured by FIT variables, also have a protective effect on the stress experienced when coping with an ASC.

Table 3.4 shows the results of Pearson's correlations that were carried out between scores on FIT variables and self-reported levels of depression and anxiety. Table 3.4 shows several significant associations between FIT variables and stress scores for adults with ASCs. The correlations suggest that scoring high on cognitive FIT variables is associated with lower levels of depression and anxiety. To understand whether personal strengths in cognitive FIT variables protect people from negative outcomes, correlations between stress scores and family functioning were repeated controlling for the effect of FIT Integrity (a composite score of the Constancies). These correlations are reported in table 3.5.

**Table 3.4.** Results of Pearson's correlations for adults with ASCs between FIT Science variables and scores on the Thoughts and Feelings Scale

	Depression	Anxiety
FIT Integrity	57**	53**
Awareness	15	37**
Self-responsibility	46**	34**
Fearlessness	52**	59**
Conscience	38**	25*
Balance	37**	19
Behavioural Flexibility	.19	05

<sup>\*</sup> Correlation is significant at 0.05, one-tailed

<sup>\*\*</sup> Correlation is significant at 0.01, one-tailed

**Table 3.5.** Results of Pearson's correlations between scores on the Family Assessment Device (FAD) and the Thoughts and Feelings scale for adults with ASCs controlling for FIT Integrity

FAD Scale	Depression	Controlling	Anxiety	Controlling
		for FIT		for FIT
		Integrity		Integrity
Problem Solving	.38**	.27*	.28*	.15
Communication	.32*	.24*	.29*	.20
Roles	.39**	.11	.39**	.14
Affective Responsiveness	.52**	.38**	.46**	.32
Affective Involvement	.36**	.21	.37**	.23
Behaviour Control	.06	03	13	25*
General Family Functioning	.37**	.31*	.38**	.32*

<sup>\*</sup> Correlation is significant at 0.05, one-tailed

Table 3.5 shows that after partialling out the effect of FIT Integrity, several correlations between family functioning in areas of the McMaster Model with anxiety scores are no longer significant. The correlation between general family functioning and levels of anxiety remained significant even when controlling for FIT Integrity. The strength of the correlation was however reduced. A similar pattern of results was observed for correlations between areas of family functioning and depression. The results suggest that FIT variables might mediate the impact of some areas of family life on the experience of stress in adults with ASCs, but this was not to the degree observed in study one.

## 3.5.4 What is the relationship between FIT variables and family habits?

The final analyses investigated the relationship between FIT variables and family habits. Study one suggested that the habit scales comprising the Family Habit Assessment Tool measure something distinct from the general family functioning scale of the Family Assessment Device. Furthermore, study one also suggested that FIT variables were associated with more effective behaviours in family life, although the correlation between FIT variables and ineffective family habits failed to reach

<sup>\*\*</sup> Correlation is significant at 0.01, one-tailed

significance. The study had anticipated that people scoring low on FIT variables might report significantly more ineffective habits in family life. Based on the findings of study one, this research also sought to explore the relationship between FIT variables and family habits. In doing so, the study also retested the conceptual appropriateness of using the family habit scales as distinct from the general family functioning scale.

Table 3.6 presents the results of Pearson's correlations that were carried out between scores on the habit scales, scores on the general family functioning scale from the Family Assessment Device and variables measured by The FIT Profiler. As found in study one, scores in general family functioning were positively correlated with ineffective family habits (r(50) = 0.90, p < 0.001, one-tailed) and negatively correlated with effective family habits (r(50) = -0.90, p < 0.001, one-tailed). However, data from adults with ASCs showed very high correlations between scores on the habit scales and the general functioning scale. This suggests that the habit scales are not measuring distinct constructs in this study. Essentially, the data suggests that the habit scales are treated similarly to the general functioning scale itself. The habit scales therefore provide less insight into the nature of family behaviours in this group.

Table 3.6 also shows the personal strengths of Awareness and Fearlessness are significantly associated with the nature of family behaviours. Adults with ASCs scoring high on Awareness reported more effective family habits (r(50)=.28, p=0.02, one-tailed). Scoring high on Awareness was also associated with perceiving fewer ineffective habits in family life (r(50)=.33, p=0.01, one-tailed). A similar pattern of results was observed for the relationship between Fearlessness and infective family habits. The results provide some evidence that strengths in cognitive FIT variables are related to the types of behavioural habits present in family life. However, the correlations might also reflect the association between FIT variables and general family functioning reported in table 3.3.

**Table 3.6.** Pearson's correlations for adults with ASCs between measures from the Family Habit Assessment Tool (FHAT), the Family Assessment Device (FAD) and The FIT Profiler

	Effective Family Habits	Ineffective Family Habits
FAD:		
General Functioning	90**	.90**
FIT Profiler:		
FIT Integrity	.18	20
Awareness	.28*	33**
Self-responsibility	.23	17
Fearlessness	.23	27*
Conscience	16	.09
Balance	01	.06
Behavioural Flexibility	22	.06
FHAT:		
Effective Family Habits	-	72**

<sup>\*</sup> Correlation is significant at 0.05, one-tailed \*\* Correlation is significant at 0.01, one-tailed

#### 3.6. Discussion

This study explored how adults affected by ASCs perceive their family functioning, with the aim of testing whether adults scoring high on FIT variables perceive fewer problems in family life. The study also explored whether strengths measured by FIT variables are associated with the experience of lower levels of personal stress. Past research into the impact of ASCs on the family has predominantly focused on understanding how parents and siblings perceive the family environment and are personally affected by having a family member with an ASC. This line of research has shown that parents, especially mothers of children with ASCs, experience high levels of psychological distress, and that families report many problems in functioning well (e.g. see Olsson & Hwang, 2001; Sanders & Morgan, 1997). Few studies have investigated how adults with ASCs perceive their family functioning and how these perceptions are related to personal outcomes. This makes it difficult to understand and promote coping with family life for people affected by ASCs.

## 3.6.1 Family Functioning

This study, to the researcher's knowledge, is the first to document how adults with ASCs perceive their family functioning. The sample of adults with ASCs who took part in the research reported very negative perceptions of family functioning in all areas of the McMaster Model. Just over 21% of adults with ASCs perceived their general family functioning as effective. Applying the same criteria, Miller et al (1985) reported that 41% of families with a psychiatric member function effectively. Data from a matched control group from a study one showed that over 55% of participants perceived their general family functioning as effective. When data was explored using criteria achieving higher (83%) diagnostic accuracy, only 36.5% of adults with ASCs were found to perceive their families as functioning effectively. Emerson and Hatton (2007) suggest that families with general functioning scores on the Family Assessment Device above 2.5 have higher risk of children with intellectual disabilities developing emotional disorders. In this study, just over 48% of adults with ASCs scored equal to or above 2.5 in general family functioning. Taken together the results suggest that adults with ASCs perceive their

families as experiencing more problems in functioning well compared to data from psychiatric groups, and a normative sample. Whilst the comparisons between adults with ASCs and psychiatric groups drawn here are not matched for sex, age, family structure and social economic status, research with parents generally supports this trend. Parents of children with ASCs report more stress in the family environment than parents of children with other disabilities, but both groups generally report more stress than matched controls (e.g. see Sanders and Morgan, 1997).

## 3.6.2 Family functioning, personal stress and FIT variables

The results of the study also supported the findings of study one of participants without ASCs. This study found significant correlations between how adults with ASCs perceived their family functioning in areas of the McMaster Model and their level of personal stress. This suggests that how adults with ASCs perceive their family functioning is indeed related to the experience of psychological distress. This is consistent with past research showing that family variables such as cohesion and conflict are related to the psychological outcomes for children with chronic health conditions (Kazak & Drotar, 1997).

The study also suggests that adults with ASCs scoring high on FIT variables reported fewer problems in family functioning, and lower levels of personal stress. There was also some evidence to suggest that the personal strengths of Awareness and Fearlessness might be important in mediating the impact of family functioning on the experience of depression and anxiety. This suggests that interventions designed to help expand thinking and behaviour might be effective in developing resilience in adults with ASCs. Most interventions designed to improve the family environment in the context of ASCs have focused on skills training in parents, and in reducing problem behaviours in children. These results support the need for interventions that target the personal strengths of individuals that might enable them to cope across situations. Together with the results of study one, study two suggests that there may be value in improving the personal FIT Science related strengths in order to improve how people perceive their families and also their own levels of stress.

## 3.6.3 FIT variables and family habits

The study also revealed useful findings relating to the relationship between family functioning, family habits and FIT variables. Study one provided evidence to suggest that the family habit scales, which comprise the Family Habit Assessment Tool, measure something distinct to the general family functioning scale of the Family Assessment Device. Although the effective and ineffective family habit scales correlated moderately with scores on the general functioning scale, these correlations were not particularly high. In this study, the family habit scales were highly correlated with scores on the general family functioning scale. The correlation between general functioning and effective family habits was -0.9 and 0.9 with ineffective family habits. Whilst this suggests problems in family functioning are related to the perception of more habitual behaviors, it also suggests that the scales, due to multicollinearity, may not be measuring distinct constructs, at least in this sample. The correlations suggest that adults with ASCs respond to the general functioning scale, which measures agreement with scale items, in a similar way to the frequency and automaticity scales. For example, a person who strongly agrees with an item is more likely to endorse the item as a frequently occurring family behaviour and one that is relatively automatic. Data from study one, on the other hand, supported the view that general functioning items did not reflect habitual family behaviours. The habit scales appeared to be useful in differentiating between behaviours that need to be sustained (e.g. because they support family functioning and are not yet habitual) and those that need to be tackled. The results from study two suggest that the habit scales will not reveal anything more for adults with ASCs. Without further exploration of how the habit scales are used by adults with ASCs, it is not possible to interpret the nature of association between family habits, family functioning and FIT variables.

### 3.6.4 Strengths and limitations

This study was the first to report on the perceptions of adults with ASCs in relation to family functioning. There are many research studies investigating how ASCs affect family functioning from the perspective of other family members. There is however a dearth of research looking at how adults with ASC perceive family functioning and how these perceptions relate to levels of personal stress. This is very important because research elsewhere shows that family variables affect the course of disability. The research has provided further evidence to support the nature of challenges families face when coping with ASCs and shows that adults, in addition to other family members, are aware of these difficulties.

The study was also the first to explore how the personal strengths of adults with ASCs relate to personal and family outcomes, providing direction for future research. The study suggests that interventions designed to improve the personal strengths of adults with ASCs might have a positive effect on their level of stress and also improve experiences of the family. Moreover, data from The FIT Profiler suggests that the instrument reflects the nature of rigid thinking and behaviour that is characteristic of ASCs. The scores of adults with ASCs on The FIT Profiler were significantly lower than those of a normative comparison group. Further empirical testing would be useful to explore the extent to which The FIT Profiler provides insight into the core behavioural and cognitive features of people affected by ASCs. It would also be useful to compare performance on The FIT Profiler to other measures of cognitive and behavioural flexibility e.g. the Wisconsin Card Sorting Test.

The study is not however without limitations. A sample of 52 adults was recruited to take part in this study. Although this is a good sample size for a hard to reach group, the study does lack statistical power and limited the types of statistical analyses of the data. There was also an approximately equal ratio of male and female participants in this study. Autistic Spectrum Conditions are more common in males

with a reported ratio of 4:1 (Ehlers & Gilbert, 1993). The extent to which the study findings would be different if the sample was predominantly male is unclear.

A final issue raised in the study relates to finding extremely high correlations between the general family functioning scale and the family habit measures. This suggests that the scales may not be measuring distinct constructs as they are intended to and therefore limits the use of the scales with adults with ASCs without further development. This was however the first study of its nature to explore different aspects of family life from the perspective of adults with ASCs.

### 3.6.5 Conclusions

This study has shown that adults with ASCs perceive many problems in family functioning. The study has also shown that how adults with ASCs perceive family functioning is related to the experience of depression and anxiety. More importantly, the study has provided some evidence to suggest that personal strengths in areas of FIT Science might mediate how adults with ASCs perceive their families. Furthermore, personal strengths measured by FIT variables, might also mediate the relationship between perceptions of family functioning and personal stress in the context of ASCs. Taken together with research findings of study one, there maybe value in exploring how interventions promoting personal strengths affect both the family environment, and psychological outcomes for individuals facing different types of life challenges. It is particularly important to explore how developing personal strengths might support people and families at risk of reporting problems in well being.

The research programme will now move further to explore the wider application of FIT Science in families of children with ASCs. Whilst this research suggested that adults with ASCs might benefit from interventions developing personal strengths, stress in families of children with ASCs begins early on, even during the course of diagnosis (e.g. before the child's third birthday) (Sanders & Morgan, 1997). Understanding how parents cope with the challenges faced when raising a child

with an ASC might provide practical insight into how to support families at different stages of the life cycle. Understanding the correlates of and developing resilience in parents is also likely to be associated with positive outcomes for children. The next phase of research therefore investigates the extent to which parent outcomes such as perceptions of the family environment, personal and parenting stress are related to the strengths of mothers in areas of FIT Science. This research might provide insight into variables that promote coping in parents, which is known to be related to positive outcomes for children with ASCs (e.g. see Hasting & Brown, 2002).

### Chapter 4

Study three: Exploring the relationship between FIT Science variables and parenting stress

### 4.1. Introduction

This chapter reports an empirical study investigating the association between FIT variables and parenting stress for mothers of children with Autistic Spectrum Conditions (ASCs). The relationship between parenting stress and personal strengths is of interest because the daily hassles parents experience predict the status of family health (Crnic & Greenberg, 1990). Attempts at improving the overall health of the family need to consider how to promote coping with the complex nature of stresses and hassles families face. Study two supported findings in the literature on ASCs and family life showing that adults with ASCs, in addition to other family members, perceive their families as experiencing problems in functioning well. The study also found that FIT variables were associated with how adults experienced the family and self-reported levels of personal stress. With the results from study one, these findings suggest that FIT Science is useful for understanding how people facing different challenges cope with family life and are affected by the family environment. The findings might also suggest that interventions targeting the personal strengths of individuals could provide a new approach to intervening in different family contexts. For adults affected by an ASC, a suitable intervention was anticipated to be difficult to implement, although study two suggested this group might be in particular need of support. The present study was therefore carried out to explore whether or not how mothers of children with ASCs score on FIT variables is related to perceptions of family and personal outcomes. In doing so, a comparison was drawn with a group of mothers of typically developing toddlers (the control group). The control group was included to explore whether FIT variables are important for understanding outcomes in social domains for people with different life stressors. The study discusses the potential of using interventions based on FIT Science to intervene with family functioning across different contexts.

#### 4.2. Literature Review

# 4.2.1 Raising a child with a developmental disability

For most parents, the birth of a child is expected to be a joyous occasion. However, the birth of a child with a disability has generally been viewed as a tragedy from which a family might not recover (Kearney & Griffin, 2001). Family stress in the context of children with disabilities has received considerable research attention. Understanding parental stress has been especially important to help guide services designed to assist families in adapting to and coping with unique stressors (e.g. see Larson, 1998). This is in part because family variables affect the course of childhood disorders (Hauser-Cram, Warfield, Shonkoff & Krauss, 2001) and also because research suggests that parenting stress affects family functioning and the psychological health of parents (Crnic & Greenberg, 1990). Many studies have also focused on understanding the effect of different types of disabilities on the family and on the stress of parents. This is because there is growing consensus that childhood disabilities do not have a fixed effect on the family environment (Ainge,1995).

Although parenting a typically developing child can be stressful, parents of children with developmental disabilities have consistently been reported to experience higher levels of stress. The birth of a child with a developmental disability triggers a range of emotional responses in parents and the larger family system (Trute & Hiebert-Murphy, 2002). For some families, a child with a disability represents a crisis, which requires a great deal of psychological adjustment. In other families, although viewed as a negative event, the birth of such a child provides an opportunity for the psychological growth of family members and strengthens family functioning (Trute & Hiebert-Murphy, 2002). Nonetheless, a wealth of literature has focused on the negative impact of different types of disabilities on the parents, and family life.

Barker, Blacher, Crnic & Edelbrock (2002) compared the level of parenting stress reported by parents of children aged three years both with and without developmental delays. This study found that parents of children with developmental delays reported higher levels of parenting stress than parents of typically developing children. Mothers of children with intellectual disabilities also experience more stress than mothers of aged matched controls (Pearson & Chan, 1993). Comparing mothers of children with autism and or intellectual disabilities with mothers of control children, Olsson and Hwang (2001) have also shown that parenting a child with a disability is associated with depression, where disability itself does not have a deterministic effect on stress. This is because Olsson and Hwang (2001) found that depression was highest in mothers of children with autism, followed by mothers of children with intellectual disabilities. This suggests that the type of disability a child has does indeed affect the family stress experience.

Gray (2006) stated that 'as a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities' (p.970). In line with this, research suggests that parents of children with autism and related conditions report higher levels of parenting and personal stress than parents of children with Down syndrome, learning difficulties and mental retardation (Holroyd & McArthur, 1976; Sanders & Morgan, 1997). Furthermore, the stress related to caring for a child with an ASC seems to be consistent cross culturally, where mothers report similar profiles of stress, primarily related to their child's ongoing dependency, life span care and limits placed on family activity (Koegel et al, 1992). It might also be important that mothers report more stress in caring for their child than fathers and that behavioural and emotional problems seen in children with ASCs contribute more to stress in the mother, mental health problems and family dysfunction than for fathers (Herring et al, 2006). In fact, mothers of children with ASCs seem to be the most affected in the family, with reports of up to one third of mothers experiencing significant levels of depression (DeMyer, 1979). Mothers traditionally assume more responsibility for childcare and burn out in mothers may, to some

extent, also contribute to problems in marital relationships reported elsewhere (e.g. see DeMyer, 1979).

# 4.2.2 Coping as a parent

Whilst some conditions have the potential to disrupt the family environment more than others, one fact, the significance of which often goes unnoticed, is that many parents do cope with having a child with a disability. In fact, there are also variations in how parents adjust to raising a typically developing child. In both cases, psychologists have been interested in understanding variations in coping and in how to reduce levels of stress throughout the parent's life cycle. This is because less stress in the family environment is associated with better outcomes for parents and children (Deater-Deckard, 1998).

Stress, according to Walton (1993) is essentially within the 'eye of the beholder' (p.108). To understand the different pattern of outcomes seen across families (namely why some cope and others do not), researchers have looked to the concept of family resilience and investigated factors that promote positive coping in parents of children with and without disabilities. One avenue of research has focused on personal resources because of the idea that stress results from an imbalance of resources. That is to say, stress is not a function of stressors such as children with disabilities and general child behaviour problems, but is largely down to the parent's personal resources and coping abilities (Perry, 2005). Resources are fundamental components of Perry's (2005) model of stress in families of children with developmental disabilities. Perry (2005) identifies two types of resources: individual and family. Individual resources are related to personality and cognitive coping styles, where as family resources relate to the system as a whole and include things such as family functioning and marital satisfaction (Perry, 2005).

Similarly, the double ABCX model (McCubbin & Patterson, 1982), which has consistently been applied to understand parental stress and family functioning, also emphasizes the role of resources in promoting resilience. In the original ABCX model (Hill, 1949), (A) represented the stressor, (B) was the families exiting resource for coping, (C) was the meaning of the event for the family and (X) was the crisis. The double ABCX model on the other hand accounts for a pile up of stressors or demands (aA), differentiates between new and existing family resources (bB), (cC) is the modified meaning of the event and finally (xX) represents family adaptation to the stressor or crisis. Although this model has been widely applied in research into family stress, Perry (2005) points out that the concept of family resources is not clearly defined. Family resource is a broad concept, where as Perry (2005) calls for distinguishing between personal and family resources that can help with adaptation. This is important for many reasons. First, although most researchers use a systems approach to studying the family, research is typically carried out with individuals, suggesting that perhaps the focus should be on how individuals differ in responding to stressors and the factors related to this. After all, an accurate evaluation of family resources would need to include the views of all family members. Second, by identifying personal resources or strengths of individuals that are related to positive coping in parents of children with and without disabilities, a different avenue for intervention to that proposed by systems models of family functioning can be explored. However, if a systems perspective is taken, intervention with one part of the system should also have a positive effect on others. So for example, interventions targeted at increasing the personal strengths and resources of mothers might improve marital relationships and family resources.

## 4.3. FIT Science and parenting stress

It is possible that FIT variables are a type of 'individual resource' contributing to understanding why some parents cope with parenting a child with and without a developmental disability, whilst others do not. FIT Science might capture relevant cognitive and behavioural strengths of individuals that allow them to cope effectively with, and show resilience towards, life events such as parenting a child

and the daily hassles associated with this. Researchers in the field of stress consider stress to be multi-faceted, influenced by social, environmental and personal factors (e.g. see Kinman & Jones, 2005). It is plausible that the personal strengths reflected in FIT variables are among the 'personal' variables that influence the experience of stress, in this case, specifically in the context of parenting.

Some of the variables measured by FIT Science might be directly relevant to the management of stress in parents. For example, Walton (1993) states that self-awareness is important for parents to be aware of when they are feeling stressed and to develop a plan of how they will manage this stress. Awareness is an important cognitive strength identified by FIT Science and measured by The FIT Profiler. In addition, many studies have highlighted the association between raising children with developmental disabilities and psychological disorders such as anxiety in mothers (e.g. Hastings, 2003). The cognitive strength of Fearlessness might be relevant here, which is a characteristic that might promote coping with the uncertainties related to parenting children in general. The previous studies in this thesis have also suggested that FIT variables may be related to different aspects of family functioning, perhaps including parenting stress.

## 4.4. The Study

This study explores the relationship between parental stress and FIT variables in families with a child affected by an ASC, and also families with a typically developing child. The research will build on the findings of study two and provide further evidence of whether characteristics of the person help maintain family functioning in different contexts. The study involves two distinct groups: mothers of children with ASCs (refereed to as the ASC group) and those of typically developing children (the control group). Instead of matching the ages of the children in the two groups, a decision was taken to recruit mothers with young typically developing children (mean age of 2 years), since this age is considered a particularly difficult time by mothers (Baker-Ericzen et al, 2005). The inclusion of these groups was perceived to add value to the study of family functioning across contexts using FIT Science. A

further aim of the study is to retest the associations found in studies one and two between FIT variables, family functioning, personal stress and family habits.

# 4.4.1 Hypotheses

Based on past research, the study has 8 specific hypotheses:

- 1. Mothers of children with ASCs will experience high levels of parenting and personal stress.
- 2. The levels of stress in mothers of children with ASCs will be higher than mothers of typically developing children.
- 3. Mothers scoring high on FIT variables will experience less parenting stress.
- 4. The personal strengths of mothers, as measured by FIT variables, will predict their total level of parenting stress.
- 5. Mothers scoring high on FIT variables will report their family functioning as more effective than mothers scoring low on FIT variables.
- 6. The personal strengths of mothers will be predictive of how they view their overall family functioning.
- 7. The personal strengths of mothers will mediate the relationship between family functioning and personal stress.
- 8. The personal strengths of mothers will be associated with the types of habits present in family life. It is expected that mothers scoring high on FIT variables will perceive their families to be characterized by more effective family habits.

#### 4.5. Method

### 4.5.1 Participants

Eighty-eight mothers took part in this study. There were two groups: 33 mothers of children with ASCs and 55 mothers of typically developing toddlers. Only mothers were recruited because they tend to assume more responsibility for child rearing, especially in the case of children with developmental disabilities (e.g. Bristol, Gallagher & Schopler, 1988). Mothers of children with ASCs had a modal age of 31-40 years (48.5%), followed by 41-50 years (42.4%). Just over 93% of mothers of children with ASCs were White British and predominantly described their family structure as nuclear (81.8%). Fifteen percent of mothers were single-parents. The children with ASCs involved in this study had a mean age of 7 and a half years (M=7.57 years, SD=2.96). Eighty-five percent of children were male and the average score of children on the Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1988) was 36.83 (SD= 5.92). Thirteen children scored in the mild to moderate and 16 children scored in the moderate to severe autism range of the Childhood Autism Rating Scale. Four children also had scores on the Childhood Autism Rating Scale that fell in the 'no autism' range. However, the mothers of these children were not excluded from the study as they had responded 'yes' to the question: 'has a doctor or health professional ever told you that your child has an autistic spectrum condition?' Montes & Halterman (2007) state that questions such as these yield accurate estimates of prevalence rates. As such, it cannot be said with any certainty that these children did not have autism or a related condition such as Asperger syndrome.

Mothers of typically developing children had a modal age of 31-40 (49.1%), followed by 41-50 years (38.2%). Just over 83% of mothers were White British and predominantly described their family structure as nuclear (67.3%) or single-parent (14.5%). The typically developing children were aged on average 2 and a half years (M=2.45 years, SD=0.50) and 52.7% of children were male and 47.3% were female. All children were developing appropriately for their age. This was established by asking mothers to state whether 'a doctor or a health professional has ever told you

that your child has a learning disability or a developmental condition such as ADD, ADHD, Down syndrome or autism?'

The autistic children involved in this study were significantly older than typically developing toddlers (t(33.08) = 9.36, p < 0.001, two-tailed). Since the aim of the study was to explore the association between FIT variables and parenting stress in two distinct groups, this was a finding that was not expected to affect the results of the study. Where comparisons are drawn between the two groups of mothers, the aim of the study was explicitly to understand whether raising a child with an ASC was more or less difficult than raising a child in a difficult stage of life. Mothers in the two comparison groups also did not differ significantly in age ( $X^2(4, N=88) = 3.03$ , p = 0.55, two-tailed), family structure ( $X^2(3, N=88) = 4.54$ , p = 0.21, two-tailed) or in the number of children they were parenting (t(86) = 0.65, p = 0.52, two-tailed).

#### 4.5.2 Procedure

This was a questionnaire study. Mothers of children with ASCs were recruited via an advertisement placed on the National Autistic Society's website about a study into factors promoting coping in parents. Those who were interested in the study contacted the researcher and were subsequently mailed study materials and a self-addressed envelope.

Mothers of typically developing children were recruited by approaching various play groups for toddlers in Hertfordshire and asking permission to distribute information about the study to mothers of children aged 2 to 3 years. Mothers who were willing to take part in the study were asked to contact the researcher, after which they were mailed the study materials. There was an 89% completion rate for this study for mothers of children with an ASC (4 mothers did not complete the questionnaire pack) and an 82% completion rate for mothers of typically developing children (12 questionnaires were not returned).

### 4.5.3 Questionnaire Measures

All mothers were asked to complete the Parenting Stress Index- Short Form (Abidin, 1990), The FIT Profiler (Fletcher, 1999), the general family functioning scale of the Family Assessment Device (Epstein et al, 1983) and the Family Habit Assessment Tool. In addition, mothers of children with ASCs completed the Childhood Autism Rating Scale to verify their child's diagnosis. Mothers also provided various demographic details including their age, family structure and details on the age and sex of the child in reference to whom they will complete the Parenting Stress Index-Short Form. Details on The FIT Profiler, the general family functioning scale of the Family Assessment Device and the Family Habit Assessment Tool can be found in chapter two.

### 4.5.3.1 The Parenting Stress Index- Short Form

The Parenting Stress Index- Short Form (PSI-SF) is a 36-item measure of parenting stress in three areas: parental distress (PD), parent-child dysfunctional interaction (P-CDI) and difficult child (DC). The parental distress domain evaluates how much stress a parent is experiencing in their role due to personal factors such as restrictions placed on other life roles (Abidin, 1990). The parent-child dysfunctional interaction domain essentially measures the parent's perception of their child, including whether the child has a negative impact on the parent's life and whether he or she has lived up to the parent's expectations (Abidin, 1990). The difficult child domain focuses on characteristics of the child that make him or her easy or difficult to manage (Abidin, 1990). Example items corresponding to each of these subscales can be found in table 4.1. Items are rated on a 5-point scale ranging from 'strongly agree'-'strongly disagree'. Scores on specific items are summed to indicate how much stress parents experience related to different aspects of parenting. There are 12 items that comprise each of the subscales of the Parenting Stress Index-Short Form, giving each domain a possible stress score ranging from 12-60. The Parenting Stress Index- Short Form also includes a composite total stress score. The total stress score ranges from 36-180. High scores are considered more problematic and Abidin (1990) suggests that a raw score of over 90 in total parenting stress

represents a parent who is experiencing clinical levels of stress. The Parenting Stress Index-Short Form has good test-retest reliability and internal consistency and also correlates highly with the full length Parenting Stress Index (Abidin, 1995; Roggman, Moe, Hart & Forthun, 1994).

**Table 4.1.** Example items from the Parenting Stress Index- Short Form (PSI-SF)

PSI-SF Subscale	Example Items
Parental Distress	'I often have the feeling that I cannot handle things well.'
	'I feel trapped by my responsibilities as a parent.'
	'I feel alone and without friends'.
Parent-Child	'Sometimes I think my child doesn't like me and doesn't want
Dysfunctional	to be close to me'.
Interaction	'When playing, my child doesn't often giggle or laugh.'
	'I expected to have closer and warmer feelings for my child
	than I do and this bothers me.'
Difficult Child	'My child seems to cry or fuss more often than most children.'
	'My child gets upset easily over the smallest thing.'
	'There are some things my child does that really bother me.'

### 4.5.3.2 The Childhood Autism Rating Scale

The Childhood Autism Rating Scale (CARS) is a measure of how a child's behaviour varies from a typically developing child of the same age across 14 different behavioural domains and item 15 assess general impressions of autism (see table 4.2 for a summary of domains included in the Childhood Autism Rating Scale). Items are rated from 1 (age-appropriate behaviour) to 4 (severely abnormal/autistic behaviour). Scores across all 15 items in the interval of 30 to 36.5 represent mild to moderate autism, with scores from 37 to 60 indicating severe autism. The Childhood Autism Rating Scale can be used as a diagnostic instrument or form part of the autism assessment (DiLalla & Rogers, 1994). The scale reliably identifies children with firm diagnoses of autism and has good internal-consistency, test-re-test and inter-rater reliability and criterion validity (Eaves & Milner, 1993; DiLalla & Rogers, 1994; Schopler et al, 1988).

**Table 4.2.** Domains of the Childhood Autism Rating Scale (CARS)

Relating to People	Adaptation to Change	Verbal Communication
Imitation	Visual Response	Nonverbal Communication
Emotional Response	Listening Response	Activity Level
Body Use	Taste, Smell and Touch Response and Use	Level and Consistency of Intellectual Response
Object Use	Fear of Nervousness	General Impressions of Autism

#### 4.6. Results

### 4.6.1 Descriptive statistics

Tables 4.3 and 4.4 present descriptive statistics and standard deviations (SD) for all variables measured within this study- from the Parenting Stress Index- Short Form (PSI-SF), the general family functioning scale of the Family Assessment Device (FAD), the Family Habit Assessment Tool (FHAT) and The FIT Profiler. Scale scores in each of the areas within tables 4.3 and 4.4 will be used to test the previously stated research hypotheses.

In reference to raw data presented in table 4.3 from the Parenting Stress Index – Short Form, both mothers of children with ASCs and those of typically developing children appear to be experiencing some degree of parenting stress. Subscale scores are considerably above the minimum scale score of 12. The mean total parenting stress score for mothers of typically developing children is however below the clinical cut- off of 90 (M=59.46, SD=16.75). Only four (7.3%) mothers in this group scored above the clinical cut-off. A quite different picture was revealed for mothers of children with ASCs where the data suggests very high levels of parenting stress (M=108.58, SD=18.98). Twenty-seven (81.8%) of the mothers of children with ASCs scored above the clinical cut-off for total parenting stress. A similar pattern of results is seen across subscales of the Parenting Stress Index-Short Form. Mothers of children with ASCs consistently scored higher, with the biggest between group difference relating to difficult child behaviours. The mean group scores on the difficult child subscale for mothers of children with ASCs and those in the control group were M=42.18, (SD=8.12) and M=24.53 (SD=7.59) respective.

Table 4.3 also displays data from the general family functioning scale of the Family Assessment Device. The mean scores for mothers of children with ASCs and those in the control group on the general family functioning scale were M=1.84 (SD=0.57) and M=1.98 (SD=0.42) respective. In both groups, just over 48% of mothers perceived their family functioning within the clinical range of the scale (scores above 2). Scale scores on the Family Habit Assessment Tool indicate that mothers

in both groups report the presence of more effective habits in family life. Mothers in both groups do however perceive there to be behaviours present in their families that hinder effective family functioning. Mothers of children with ASCs reported more problematic family habits (M=4.47, SD=0.82) than mother in the control group (M=3.77, SD=0.92).

**Table 4.3.** Mean (SD) scale scores for variables measured by the Parenting Stress Index-Shot Form (PSI-SF), the general family functioning scale of the Family Assessment Device (FAD) and the Family Habit Assessment Tool (FHAT)

PSI-SF/ FAD/ FHAT Subscale	ASC group mean (n=33)	Control group mean (n=55)
PSI-SF:		
Total Parenting Stress	108.58 (18.98)	59.46 (16.75)
Parental Distress	34.45 (7.42)	25.24 (8.19)
P-CDI	31.94 (7.18)	20.61 (6.10)
Difficult Child	42.18 (8.12)	24.53 (7.59)
FAD:		
General Family Functioning	1.84 (0.57)	1.98 (0.42)
FHAT:		
Effective Family Habits	5.85 (1.12)	6.41 (0.99)
Ineffective Family Habits	4.47 (0.82)	3.77 (0.92)

P-CDI= Parent Child Dysfunctional Interaction

Table 4.4 displays data from The FIT Profiler, which shows the profile of personal strengths of mothers in both groups. Scores in the Constancies range from 0 (low levels of cognitive strengths) to 10 (high levels of cognitive strengths). Behavioural Flexibility scores range from 0 to 100, with higher scores indicating more flexibility in behaviour. Tables 4.4 shows that mothers in both groups had similar scores on FIT variables and are characterized by some strengths in cognitive FIT variables and low levels of Behavioural Flexibility. The mean Behavioural Flexibility score of mothers of children with ASCs was 19.61 (SD=15.98) and for mothers in the control group the mean was 15.04 (SD=12.81).

Depression and anxiety scores both range from 4 to 16, with high scores reflecting higher levels of personal stress. Group means in table 4.4 suggest that mothers in each group are experiencing mild to moderate levels of depression and anxiety. However, the mean stress scores for mothers of children with ASCs were higher than those of mothers of typically developing toddlers. In both groups, levels of anxiety were higher than levels of depression. For depression, just over 12% of mothers in the ASC group scored in the clinical range of the scale and for anxiety, just over 30% of mothers scored in the clinical range. The scores of two mothers in the control group were in the clinical range for depression and just over 12% of mothers scored in the clinical range for anxiety. The data suggests that mothers of children with ASCs were experiencing higher levels of personal stress than mothers of typically developing children.

Table 4.4. Mean (SD) scale scores for variables measured by The FIT Profiler

FIT Profiler Subscale	ASC group mean	Control group mean
	(n=33)	(n=55)
FIT Integrity	62.22 (10.38)	60.02 (9.31)
Awareness	6.47 (0.96)	6.12 (1.02)
Self-responsibility	6.50 (1.39)	6.32 (1.06)
Fearlessness	4.97 (2.20)	5.08(2.01)
Conscience	7.98 (1.22)	7.16 (1.52)
Balance	5.17 (1.09)	5.32 (1.12)
Behavioural Flexibility	19.61 (15.98)	15.04 (12.81)
Depression	9.42 (2.64)	7.49 (2.74)
Anxiety	10.90 (2.74)	9.01 (2.77)

# 4.6.2 Do mothers of children with Autistic Spectrum Conditions experience more parenting and personal stress than mothers of typically developing children?

The first analyses explored differences in levels of parenting and personal stress experienced by mothers of children with ASCs and those of typically developing children. Group means in table 4.3 and 4.4 suggest that both parenting and personal stress is higher in mothers of children with ASCs. Independent samples t-tests were carried out comparing group scores on subscales of the Parenting Stress Index-Short Form and the Thoughts and Feelings Scale of The FIT Profiler. Subscale scores were entered as dependent variables and group (ASC or Control) was entered as the independent variable. Table 4.5 presents the results of the independent samples t-tests.

The results in table 4.5 show that mothers of children with ASCs experience significantly more parenting and personal stress than mothers of typically developing children. Mothers of children with ASCs consistently reported experiencing significantly more parenting stress in all areas of the Parenting Stress Index- Short Form. For total parenting stress, there was a large effect of having a child on the autistic spectrum on the level of stress reported (t(86) = -12.66, p < 0.001, one-tailed, d = 2.74). There was also a moderate effect of having a child with autism on levels of depression (t(86) = -3.24, p < 0.01, one-tailed, d = 0.71) and anxiety (t(86) = -3.10, p < 0.01, one-tailed, d = 0.68).

**Table 4.5.** Results of independent samples t-tests comparing levels of parenting and personal stress experienced by mothers of children with ASCs and mothers of typically developing children

Subscale	t value (df=86)	Significance	Effect size (Cohen's d)	95% confidence interval
Total Parenting Stress	-12.66	.000***	2.74	2.15-3.33
Parental Distress	-5.28	.000***	0.36	-0.71-1.64
P-CDI	-7.88	.000***	1.70	1.20-2.20
Difficult Child	-10.28	.000***	2.24	1.70-2.79
Depression	-3.24	.001**	0.71	-0.27-1.16
Anxiety	-3.10	.001**	0.68	-0.24-1.12

P-CDI = Parent Child Dysfunctional Interaction

# 4.6.3 Do mothers scoring high on FIT variables experience less parenting stress?

Tables 4.6 and 4.7 display the results of Pearson's correlations that were carried out between subscales of the Parenting Stress Index-Short Form and FIT variables for mothers in both groups. Table 4.6 shows that for mothers of children with ASCs, there were several significant negative correlations between personal strengths and parenting stress. This suggests that scoring low on FIT variables is associated with higher levels of parenting stress. Awareness and Behavioural Flexibility were not significantly related to any aspect of parenting stress, although the correlation coefficients suggest a trend in the right direction. There was also a modest positive association between levels of depression and anxiety and parenting stress associated with raising a child on the autistic spectrum. This suggests that as stress in areas of life such as parenting increases, so does the personal stress experienced by mothers of children with ASCs.

<sup>\*\*</sup> Significant at p < 0.01, one-tailed

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

For mothers of typically developing children, with exception to Behavioural Flexibility, FIT variables were significantly associated with parenting stress in all areas of the Parenting Stress Index- Short Form. The correlation coefficients showed that scoring low on cognitive FIT variables is associated with higher levels of parenting stress. Furthermore, there was also a moderate positive association between levels of depression and anxiety and stress reported in subscales of the Parenting Stress Index- Short Form. Overall the results suggest that the personal strengths of mothers are associated with stress experienced when parenting a typically developing child and a child with an ASC. Finally, in both groups of mothers, stress related to parenting is also associated with general depression and anxiety.

**Table 4.6.** Pearson's correlations between subscales of the Parenting Stress Index-Short Form and FIT variables for mothers of children with ASCs

	Parental Distress	P-CDI	Difficult Child	Total Stress
Integrity	55**	23	40**	48**
Awareness	17	15	08	16
Self-responsibility	60**	24	44**	52**
Fearlessness	53**	16	36*	42**
Conscience	25	30*	31*	35*
Balance	32*	01	20	21
Behavioural Flexibility	05	02	04	01
Depression	.75**	.45**	.43**	.65**
Anxiety	.73**	.32*	.50**	.62**

P-CDI= Parent-Child Dysfunctional Interaction

<sup>\*</sup> Correlation is significant at 0.05, one-tailed

<sup>\*\*</sup> Correlation is significant at 0.01, one-tailed

**Table 4.7.** Pearson's correlations between subscales of the Parenting Stress Index-Short Form and FIT Science variables for mothers of typically developing children

	Parental Distress	P-CDI	Difficult Child	Total Stress
Integrity	67**	54**	59**	60**
Awareness	44**	34**	27*	36**
Self-responsibility	44**	43**	51**	38**
Fearlessness	39**	38**	37**	41**
Conscience	53**	30*	45**	42**
Balance	52**	40**	41**	49**
Behavioural Flexibility	.08	.17	.15	.12
Depression	.55**	.56**	.41**	.51**
Anxiety	.49**	.52**	.45**	.53**

P-CDI= Parent Child Dysfunctional Interaction

## 4.6.4 Are the personal strengths of mothers predictive of total parenting stress?

Regression analyses were carried out to investigate whether the personal strengths of mothers predict their level of total parenting stress. For each group of mothers, a multiple regression analysis was carried out, in which total parenting stress was entered as the dependent variable. FIT variables in tables 4.6 and 4.7 that were significantly correlated with total parenting stress were entered as predictor variables. For mothers of children with ASCs, this means that Self-responsibility, Fearlessness and Conscience were entered as predictor variables. For mothers of typically developing children, table 4.7 shows that all of the Constancies were significantly associated with total parenting stress. FIT Integrity was therefore used as a predictor variable.

<sup>\*</sup> Correlation is significant at 0.05, one-tailed

<sup>\*\*</sup> Correlation is significant at 0.01, one-tailed

## 4.6.4. 1 Predicting total parenting stress in mothers of children with Autistic Spectrum Conditions

Using the enter method, total parenting stress was predicted in mothers of children with ASCs using Self-responsibility, Fearlessness and Conscience as predictor variables. This model accounted for 30.6% of variability in total parenting stress. Analysis of the model parameters showed that only Self-responsibility significantly contributed to the model. The regression was therefore carried out again including Self-responsibility as the only predictor of total parenting stress. The results of the second regression showed that Self-responsibility accounted for 27.1% of variability in the total parenting stress (t(31) = -3.39, p = 0.001, one-tailed).

**Table 4.8.** Coefficients of the regression models predicting total parenting stress in mothers of children with ASCs

Model predictors	Unstandardized coefficients	t-value	Significance
Model 1			
Constant	169.43		
Self-responsibility	-5.38	-1.78	0.04*
Fearlessness	75	39	0.34
Conscience	-2.76	-1.06	0.14
Model 2			
Constant	154.77		
Self-responsibility	-7.09	-3.39	0.001*

<sup>\*</sup> Significant at p < 0.05, one-tailed

Individual regression analyses were also carried out to explore the amount of variability in different areas of parenting stress that might be attributed to the personal strengths of mothers. For these analyses, subscales scores were treated as dependent variables and FIT variables significantly associated with areas of stress were entered as predictor variables.

<sup>\*\*</sup> Significant at p < 0.01, one-tailed

The results of the analyses are presented in tables 4.9, 4.10 and 4.11. Self-responsibility was the only significant predictor of parental distress (t(31) = -2.95, p < 0.01, one-tailed) and accounted for 24.4 % of variability in scores on the parental distress subscale. Conscience was the only FIT variable significantly correlated with stress in the area of parent-child dysfunctional interaction and accounted for 9.2% of variability of stress (t(31) = -1.77, p = 0.04, one-tailed). FIT variables did not significantly predict stress on the difficult child subscale. Overall this suggests that the personal strengths of mothers are predictive of stress related to problems mothers experience in their role as a function of personal factors (parental distress) and stress associated with parent-child dysfunctional interactions. However, stress associated with how difficult the autistic child's behavior is perceived to be cannot be predicted using the personal strengths of mothers.

**Table 4.9.** Coefficients of the regression models predicting scores on the parental distress subscale of the Parenting Stress Index-Short Form for mothers of children with ASCs

Model Predictors	Unstandardized coefficients	t	Significance
Model 1			
Constant	53.28		
Self-responsibility	22	-2.24	0.01*
Fearlessness	77	-1.02	0.15
Balance	.18	.15	0.44
Model 2			
Constant	144.39		
Self Responsibility	-5.18	-2.95	0.001**

<sup>\*</sup> Significant at p < 0.05, one-tailed

<sup>\*\*</sup> Significant at p < 0.01, one-tailed

**Table 4.10.** Coefficients of the regression model predicting scores on the parentchild dysfunctional interaction subscale of the Parenting Stress Index- Short Form for mothers of children with ASCs

Model predictors	Unstandardized coefficients	t	Significance
Constant	46.10		
Conscience	-1.77	-1.77	0.04*

<sup>\*</sup> Significant at p < 0.05, one-tailed

**Table 4.11.** Coefficients of the regression model predicting scores on the difficult child subscale of the Parenting Stress Index Short Form for mothers of children with ASCs

Model predictors	Unstandardized coefficients	t	Significance (one-tailed)
Constant	65.06		<u> </u>
Self-responsibility	-1.88	-1.38	0.08
Fearlessness	28	33	0.37
Conscience	-1.14	98	0.16

4.6.4.2 Predicting total parenting stress in mothers of typically developing children For mothers of typically developing children, total parenting stress was predicted using FIT Integrity, given that all of the Constancies were significantly negatively correlated with total parenting stress (see table 4.7). The results of the regression showed that the cognitive strengths of mothers were significantly predictive of total parenting stress (t(53) = -5.56, p < 0.001, one tailed) and accounted for 36.9% of variability in total parenting stress.

**Table 4.12.** Coefficients of the regression model predicting total parenting stress in mothers of typically developing children

Model Predictors	Unstandardized Coefficients	t	Significance (one-tailed)
Constant	125.04		
FIT Integrity	-1.09	-5.56	0.001**

<sup>\*\*</sup> Significant at p < 0.01, one-tailed

### 4.6.5 FIT variables and parenting stress in mothers as a group (N=88)

The results so far have shown that total parenting stress in mothers of typically developing children can be significantly predicted based on cognitive strengths on FIT variables. Additionally, there is also evidence to suggest that some of the personal strengths of mothers of children with ASCs predict their total parenting stress and stress related to parental distress and parent-child dysfunctional interactions. Taken together, the results suggest that FIT variables are useful in understanding the parental stress experienced by both groups.

Past research has assumed children with disabilities have a negative effect on parents. To further demonstrate that the characteristics of parents influence their level of stress, a final regression analysis was carried out. This regression aimed at predicting parenting stress based on the type of child (ASC or Control) and the personal strengths of mothers, as measured by FIT variables.

A regression was carried out using the stepwise method and entering total parenting stress as the dependent variable, and group (ASC or Control) and FIT Integrity as predictor variables. FIT Integrity was entered as a predictor variable because a correlation for the sample as a whole (N=88) showed this to be significantly related to total parenting stress (r(86) = -0.23, p = 0.01, one-tailed). Behavioural Flexibility was not entered as a predictor variable because it was not significantly correlated with total parenting stress (r(86) = 0.16, p = 0.06, one-tailed).

The results of the stepwise regression are shown in table 4.13. The first step of the analysis suggests that group (ASC or Control) is a significant predictor or total parenting stress. This was expected owing to the findings of past research into the stress experienced by mothers of children with ASCs and other disabilities. Group accounted for 65.1% of variability in total parenting stress. However, step two of the regression, including group and FIT Integrity as predictor variables, showed that FIT Integrity significantly accounted for a further 10.7% of variability in total parenting stress. This is strong evidence supporting the role of FIT variables in understanding parental stress across different contexts.

**Table 4.13.** Results of the stepwise regression predicting total parenting stress in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R change
Step 1						
Constant	10.35					
Group	49.11	12.66	0.000***	160.27	0.000***	0.65
Step 2						
Constant	68.24					
Group	51.31	15.68	0.000***			
FIT-	-1.00	-6.11	0.000***	132.75	0.000***	0.10
Integrity						

<sup>\*\*\*=</sup> Significant at p < 0.001, one-tailed

Stepwise regressions were also carried out with the aim of predicting stress in each area of the Parenting Stress Index-Short Form for the sample as a whole. Table 4.14 displays the results of Person's correlations used to establish which FIT variables to enter in individual regressions as predictor variables.

**Table 4.14.** Pearson's correlations between FIT Integrity, Behavioural Flexibility and stress in the subscales of the Parenting Stress Index- Short Form for the whole sample of mothers (N=88)

	FIT Integrity	Behavioural Flexibility
Parental Distress	-0.48**	0.10
P-CDI	-0.23*	0.16
Difficult Child	-0.26*	0.18*

<sup>\*</sup> Correlation significant at 0.05, one-tailed

The results of the stepwise regressions are summarized below. In each regression, group was a significant predictor of parenting stress in subscales of the Parenting Stress Index- Short Form. In addition, the cognitive strengths of mothers were also maintained as significant predictors of parenting stress. This suggests that whether or not a mother has a child with a developmental disability, as well as personal strengths, affect the experience of parenting stress. The coefficients of the stepwise regressions suggest that personal strengths in cognitive FIT variables protect mothers from experiencing higher levels of parenting stress.

<sup>\*\*</sup> Correlation significant at 0.01, one-tailed

**Table 4.15.** Results of the stepwise regression predicting scores on the parental distress subscale of the Parenting Stress Index- Short Form in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R square
Step 1						
Constant	16.01					
Group	9.21	5.28	0.000***	27.95	0.000**	0.24
Step 2						
Constant	45.43					
Group	10.33	7.50	0.000***			
FIT-	-0.50	-7.37	0.000***	49.88	0.000**	0.54
Integrity						

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

**Table 4.16.** Results of the stepwise regression predicting scores on the parent-child dysfunctional interaction subscale of the Parenting Stress Index- Short Form in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R square
Step 1						
Constant	9.28					
Group	11.32	7.88	0.000***	62.09	0.000***	0.41
Step 2						
Constant	25.15					
Group	11.93	8.98	0.000***			
FIT-	-0.27	-4.13	0.000***	45.37	0.000***	0.51
Integrity						

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

**Table 4.17.** Results of the stepwise regression predicting scores on the difficult child subscale of the Parenting Stress Index- Short Form in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R square
Step 1						
Constant	6.87					
Group	17.65	10.28	0.000***	105.77	0.000***	0.55
Model 2						
Constant	30.73					
Group	18.56	12.46	0.000***			
FIT-	-0.41	-5.53	0.000***	86.47	0.000***	0.67
Integrity						

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

NB- The stepwise regression removed Behavioural Flexibility from the model, therefore only 2 steps are reported.

# 4.6.6 Do mothers scoring high on FIT variables perceive their general family functioning as more effective?

This study aimed to retest the relationship between perceptions of family functioning and FIT variables reported earlier in this thesis. Pearson's correlations between scores on the general family functioning scale of the Family Assessment Device with FIT variables were carried out. Table 4.18 displays the results of the correlations that were carried out. In both groups, the negative association between general family functioning and cognitive strengths of mothers was confirmed. For mothers of children with ASCs, Self-responsibility, Fearlessness and Balance were significantly correlated with general family functioning. Behavioural Flexibility was also significantly related to perceptions of general family functioning (r(31) = -0.41, p < 0.01, one-tailed). Mothers scoring high on Behavioural Flexibility perceived their family as functioning more effectively.

For mothers of typically developing children, cognitive strengths measured by FIT variables, were significantly associated with general family functioning. Behavioural Flexibility was not significantly correlated with how mothers perceived their family functioning (r(53)=-0.03, p =0.39, one-tailed). Overall, the results in table 4.18 support the role of FIT variables in how mothers of children with ASCs and mothers of and typically developing children perceive their family functioning.

**Table 4.18.** Pearson's correlations between scores on the general family functioning scale of the Family Assessment Device and FIT Science variables for mothers of children with ASCs and typically developing children

	General family functioning ASC group	General family functioning Control group
FIT Integrity	48**	49**
Awareness	16	29*
Self-responsibility	48**	46**
Fearlessness	43**	24*
Conscience	20	47**
Balance	42**	26*
Behavioural Flexibility	41**	03
Depression	.29*	0.42**
Anxiety	.24	0.33**

<sup>\*</sup> Correlation significant at p < 0.05, one-tailed

# 4.6.7 Do scores on FIT variables predict how mothers view their general family functioning?

The next analyses explored whether personal strengths, measured by FIT variables, significantly predict how mothers perceive their general family functioning. Two regressions were carried. In each regression, general family functioning was the dependent variable and for mothers of children with ASCs, the predictor variables were Self-responsibility, Fearlessness, Balance and Behavioural Flexibility. For mothers of typically developing children, FIT Integrity was entered as a predictor variable.

<sup>\*\*</sup> Correlation is significant at p < 0.01, one-tailed

Tables 4.19 and 4.20 show the results of the regression analyses. For mothers of children with ASCs, Behavioural Flexibility was the only significant predictor of general family functioning, accounting for 17.1% of variability in how mothers perceived their families (t(29) = -2.53, p = 0.01, one-tailed). This provides additional support for considering the role of FIT variables in how mothers experience the family, even when facing unique stressors such as those associated with parenting a child with an ASC. For mothers of typically developing children, cognitive strengths significantly predicted 24.2% of variability in scores on the general family functioning scale (t(54) = -4.11, p < 0.001, one-tailed).

**Table 4.19.** Coefficients of the regression models predicting scores on the general family functioning of the Family Assessment Device for mothers of children with ASCs

Model predictors	Unstandardized coefficients	t	Significance
Model 1			
Constant	3.41		
Self-responsibility	12	-1.40	0.08
Fearlessness	02	39	0.34
Balance	08	85	0.20
Behavioural Flexibility	01	-2.07	0.02*
Model 2			
Constant	2.13		
Behavioural Flexibility	01	-2.53	0.01*

<sup>\*</sup> Significant at p < 0.05, one-tailed

**Table 4.20.** Coefficients of the regression model predicting scores on the general family functioning scale of the Family Assessment Device for mothers of typically developing children

Model predictors	ctors Unstandardized coefficients		Significance
Constant	3.33		
FIT Integrity	-0.02	-4.11	0.000***

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

# 4.6.8 Do personal strengths predict how mothers as a group (N=88) perceive their family functioning?

A final regression was carried out to explore the amount of variability in family functioning attributed to the nature of the child (ASC or Control), and the personal strengths of mothers for coping. Past research has shown that families of children with developmental disabilities experience more problems in family functioning. The group means in table 4.3 however suggest that the sample of mothers of children with ASCs in this study reported similar perceptions of family functioning to mothers in the control group. This suggests that personal strengths, rather than group membership, may contribute to how mothers think about family life.

To explore if this is the case, a correlation matrix was constructed to see whether for the whole sample of mothers (N=88), FIT variables were significantly correlated with scores on the general family functioning scale. The results showed a negative correlation between family functioning and FIT Integrity (t(86) = -0.49, p < 0.001, one-tailed), and Behavioural Flexibility (t(86) = -0.24, p = 0.01, one-tailed). The correlations suggest that mothers scoring high on FIT variables perceive their families as functioning more effectively. FIT Integrity, Behavioural Flexibility and group (ASC or control) were therefore entered into a stepwise regression to predict overall family functioning for the sample as a whole. The results of the stepwise regression are shown in table 4.21. As suggested, in this sample, group membership

did not contribute to predicting perceptions of overall family functioning. The variable was consequently excluded from the stepwise regression. However, scores in cognitive and behavioural FIT variables significantly contributed to predicting 28.5% of variability in perceptions of family functioning.

**Table 4.21.** Results of the stepwise regression predicting scores on the general family functioning scale of the Family Assessment Device in the sample of mothers as a whole (N=88)

Model predictors	Unstandar dized coefficient s	t	Significance	Model F statistic	Significance	Model R square
Step 1						
Constant	3.43					
<b>FIT-Integrity</b>	-0.02	-5.25	0.000***	27.58	0.000***	0.24
Step 2						
Constant	3.51					
FIT-Integrity	-0.02	-5.20	0.000***			
Behavioural	-0.01	-2.24	0.00***	16.96	0.000***	0.04
Flexibility						

<sup>\*\*\*</sup>Significant at p < 0.001, one-tailed

### 4.6.9 Family functioning, personal stress and FIT variables

Table 4.18 shows that levels of depression in mothers of children with ASCs (r(33)=0.29, p=0.04, one-tailed) and typically developing children (r(55)=0.42, p=0.001, one-tailed) were significantly related to perceptions of general family functioning. Mothers who perceived their family functioning as more problematic reported higher levels of depression and anxiety. For mothers of typically developing children, there was a similar pattern of results for levels of anxiety and perceptions of general family functioning (r(53)=0.33, p=0.01, one-tailed). For mothers of children with ASCs, anxiety was not significantly correlated with family functioning, although the correlation coefficient was in the anticipated direction (r(31)=0.24, p=0.08, one-tailed).

Significant correlations between depression, anxiety and general family functioning were repeated controlling for the effect of FIT Integrity. This is because research using FIT Science has consistently shown a link between FIT Integrity and personal stress. The link between FIT Integrity and personal stress was also demonstrated earlier within this thesis. Furthermore, studies one and two demonstrated that the relationship between family stress and personal stress is mediated by strengths in cognitive FIT variables. To retest this finding, partial correlations were carried out between general family functioning and stress, controlling for FIT Integrity. The results of the partial correlations are presented in table 4.22.

The partial correlations suggest that after controlling for FIT Integrity, there was no longer a significant association between levels of personal stress and family functioning. This suggests, as found previously, that the cognitive strengths of mothers meditate the relationship between stress and family functioning.

**Table 4.22.** Correlations between general family functioning and depression and anxiety prior to and after controlling for FIT Integrity

	General family functioning	Controlling for FIT Integrity
ASC Group		
Depression	.29*	07
Anxiety	.24	20
Control Group		
Depression	.42**	.19
Anxiety	.33**	.06

<sup>\*</sup> Correlation significant at p < 0.05, *one-tailed* 

<sup>\*\*</sup> Correlation significant at p < 0.01, one-tailed

### 4.6.10 Personal stress and strengths on FIT variables

Past research shows that mothers of children with ASCs experience high levels of personal stress. Within this study, mothers of children with ASCs also scored higher in depression and anxiety than mothers of typically developing children. However, it is important to understand the extent to which characteristics of the child determine psychological stress over a mother's own resources for coping. The results of this study support both the role of children with disabilities, and FIT variables, in the experience of parenting stress and stress in the family.

Two stepwise regressions were carried out to see if group membership and cognitive strengths significantly predict the general levels of personal stress experienced by mothers (N=88). Cognitive strengths were selected given the established link between FIT Integrity and stress.

The results of the stepwise regressions are presented in tables 4.23 and 4.24. The results suggest that levels of depression and anxiety are significantly predicted by strengths on FIT variables, as well as characteristics of children (ASC or Control). For depression, the variables together accounted for 39.5% of variability and for anxiety, the variables accounted for 44.2% of variability in stress scores. This suggests that parenting a child with a disability influences the experience of psychological distress. However, strengths on cognitive FIT variables contributed more to determining stress in each case than characteristics of children. For example, although group membership and FIT Integrity explained just over 39% of variability in depression scores, 23.6% of variability was explained by FIT Integrity alone. Overall, group added less to the model r square change than FIT Integrity. This suggests that independent of the characteristics of the child, the personal resources of mothers for coping affect the experience of stress.

**Table 4.23.** Results of the stepwise regression predicting depression scores in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R square
Step 1						
Constant	17.04					
FIT-	-0.14	-5.28	0.000***	27.91	0.000***	0.24
Integrity						
Step 2						
Constant	14.66					
FIT -	-0.15	-6.33	0.000***			
integrity						
Group	2.28	4.58	0.000***	27.73	0.000***	0.15

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

**Table 4.24.** Results of the stepwise regression predicting anxiety scores in the sample of mothers as a whole (N=88)

Model predictors	Unstandardized coefficients	t	Significance	Model F statistic	Significance	Model R
						square
Step 1						
Constant	19.69					
FIT-	-0.16	-6.09	0.000***	37.14	0.000***	0.30
Integrity						
Step 2						
Constant	17.35					
FIT-	-0.17	-7.24	0.000***			
Integrity						
Group	2.24	4.62	0.000***	33.65	0.000***	0.14

<sup>\*\*\*</sup> Significant at p < 0.001, one-tailed

# 4.6.11 Do mothers scoring high on FIT variables perceive more effective habits in family life?

The final analyses that were carried out explored the associations between FIT variables and measures derived from the Family Habit Assessment Tool. The Family Habit Assessment Tool measures the effective and ineffective habits of family members. For mothers in both groups, Pearson's correlations were carried out between family habit measures, general family functioning and scores on FIT variables. The results of the correlations are displayed in tables 4.25 and 4.26.

Table 4.25 shows that there were no significant correlations between Family Habit Assessment Tool measures and scores on FIT variables for mothers of children with ASCs. The correlation coefficients however showed a trend in the right direction. General family functioning was negatively correlated with effective family habits and positively correlated with ineffective family habits, although the correlations failed to reach significance. As proposed in study one, the family habits scales therefore appear to measure distinct constructs to the general family functioning agreement scale.

The personal strengths of mothers of typically developing children were significantly related to the presence of both effective and ineffective family habits (see table 4.26). All of the Constancies were significantly positively correlated with effective family habits. This suggests that cognitive strengths are related to behaving appropriately in a range of situations, including those relevant for family functioning. Scoring low on the Constancies was significantly negatively associated with the presence of ineffective family habits. This suggests that for mothers of typically developing children, personal strengths are important to developing the right kinds of behaviours for coping with family life. For mothers of children with ASCs, it is less clear how family habits relate to a mother's own resources for coping.

**Table 4.25.** Pearson's correlations between Family Habit Assessment Tool measures, scores of the general family functioning scale of the Family Assessment Device and FIT variables for mothers of children with ASCs

	Effective family habits	Ineffective family habits
General Family Functioning	-0.02	0.34
FIT Integrity	0.04	-0.21
Awareness	0.09	-0.12
Self-responsibility	0.26	0.001
Fearlessness	0.04	-0.21
Conscience	-0.01	-0.08
Balance	0.02	-0.36
Behavioural Flexibility	-0.01	-0.13
Effective Family Habits	-	-0.03

**Table 4.26.** Pearson's correlations between Family Habit Assessment Tool measures, scores on the general family functioning scale of the Family Assessment Device and FIT Science variables for mothers of typically developing children

	Effective family habits	Ineffective family habits
General Family Functioning	-0.64**	0.54**
FIT Integrity	0.60**	-0.47**
Awareness	0.35**	-0.23**
Self-responsibility	0.52**	-0.48**
Fearlessness	0.37**	-0.41**
Conscience	0.46**	-0.20
Balance	0.36**	-0.24*
Behavioural Flexibility	0.08	0.16
Effective Family Habits	-	-0.64**

<sup>\*</sup> Correlation significant at p < 0.05, one-tailed

<sup>\*\*</sup> Correlation significant at p <0.01, one-tailed

#### 4.7. Discussion

The aim of this study was to investigate whether the personal strengths of mothers, as measured by FIT variables, are related to coping with parenting stress. The results of studies one and two had shown that FIT variables were important in understanding perceptions of family functioning. In those earlier studies, FIT variables were also associated with the experience of personal stress, and the nature of family habits. This study went further to consider whether or not FIT variables are related to parenting stress, which is known to impact the functioning of the family. The results of study two also supported a consistent finding in the research literature showing that families with a member on the autistic spectrum experience many problems in functioning well. In study two, adults with ASCs were found to report many problems in the functioning of their families. This study explored the empirical association between scores on FIT variables and levels of parenting stress from the perspective of mothers of children with ASCs. The study also explored the association between FIT variables and parenting stress in mothers of typically developing children. This was with the aim of understanding whether the mechanisms involved in coping are similar in both groups. This has implications for interventions designed to support parents in both types of families. A final aim of the study was to replicate findings from studies one and two, demonstrating the role of FIT variables in perceptions of family functioning, family habits and personal stress.

### 4.7.1 The experience of parenting and personal stress

Study three found that mothers of children with ASCs experienced significantly more parenting stress than mothers of typically developing children. This is despite mothers of typically developing children parenting children who are at a demanding stage of development (toddlers). The mean total parenting stress score for mothers of children with ASCs was above the raw score of 90, which is the clinical cut-off suggested by Abidin (1990). Subsequently, many mothers were found to report total levels of parenting stress that fell in the clinical range of the scale. The mean total parenting stress score for this group was 108.5 (*SD*=18.93). Mothers of typically

developing children reported significantly lower levels of total parenting stress (*M*=59.46, *SD*=16.75). Although mothers of children with ASCs experienced significantly more parenting stress, the total stress score indicates that mothers of typically developing children were also experiencing some degree of stress. Research has, in the main, focused on the stress experienced by parents facing challenging circumstances and overlooked the fact that all parents experience some degree of stress in their role (Baker-Ericzen et al, 2005). Having a child with a developmental condition such as an ASC does however have a moderate to large effect on levels of parenting stress.

In terms of maternal levels of depression and anxiety, the study showed a moderate effect size for having a child with an ASC. Just over 30% of mothers of a child with an ASC reported clinical levels of anxiety, and 12% reported clinical levels of depression. However, the group means showed that mothers of typically developing children were also experiencing mild levels of depression and anxiety. Only two mothers in this group scored in the clinical range for depression, and 12% scored in the clinical range for anxiety. Taken together these findings suggest that parenting a child is associated with some degree of parenting and personal stress but mothers of children with ASCs are at greater risk of experiencing high levels of stress. This finding concurs with past research (e.g. see Sander and Morgan, 1997).

#### 4.7.2 FIT variables and parenting stress

A primary aim of this study was to explore the role of personal strengths in how mothers cope with being a parent. The study suggested that for mothers of children with ASCs, FIT variables were significantly associated with parenting stress. Scoring high on FIT variables was associated with lower levels of parenting stress. FIT variables also predicted how mothers perceived their total parenting stress, parental distress and the parent-child dysfunctional interaction domains of the Parenting Stress Index-Short Form. Personal strengths measured by FIT variables did not predict how difficult the autistic child's behaviour was perceived to be. This finding can perhaps be attributed to the items that comprise the difficult child

subscale of the Parenting Stress Index-Short Form. Items comprising this scale include 'my child seems to cry or fuss more often than most children and 'my child gets upset easily over the smallest thing.' The difficult child subscale includes very factual statements about the child's behaviour. Scores on this scale therefore measure actual child behaviours and children with ASCs are likely to display many of the behaviours captured in this scale, independent of a mother's own resources for coping. Other domains of the Parenting Stress Index-Short Form on the other hand measure how parenting the target child has personally affected a mother. Scores in these domains are therefore likely to be associated with how a mother manages the behaviours of her child.

For the mothers of children with ASCs, it was surprising to find that Awareness was not related to levels of parenting stress. Walton (1993) suggests that awareness is important for parents to know when they are feeling stressed and to try and improve their situation. It is suggested here that in the case of ASCs, even if mothers are aware of their level of stress, they are unable to tackle their stress because the demands being faced are constantly changing. Therefore, even if mothers are able to resolve an issue related to parenting their child, another may present itself. As such, mothers might be aware of their parenting stress but feel trapped by it because it is constantly changing and manifesting itself in different ways. Being aware of parenting stress, for this group, may not be the same as being able to cope. Evidence to support the changing nature of stresses for mothers of children with ASCs is presented in study five.

For mothers of typically developing children, strengths measured by FIT variables were also related to levels of parenting stress. Furthermore, FIT cognitive strengths accounted for over 39% of variability in how mothers perceived their levels total parenting stress. This suggests that the mechanisms promoting coping in parents are essentially similar. The strongest evidence to support the role of FIT variables in the stress mothers experience comes from the results showing that for the whole sample of mothers, parental stress could be predicted by identify (1) if a mother has

a child with an ASC and (2) knowing a mothers profile of strengths on cognitive FIT variables. Parenting stress levels were determined more by having a child with an ASC than parental FIT scores. This is to be expected from the wealth of literature on the stress levels of mothers of children with ASCs (e.g. Holroyd & McArthur, 1976; Sanders & Morgan, 1997). However, FIT variables also had a significant role to play, as shown by them independently contributing to the stepwise regression. This confirms, as Perry (2005) suggests, that factors other than child behaviour problems contribute to family stress. A similar pattern of results was observed for predicting personal stress in mothers as a group. This again suggests that it is not having a child with a disability per say that determines the effect on parents. Characteristics of parents themselves play a role in different outcomes seen across families. Other studies have also shown that parent characteristics influence the experience of stress. Hassall, Rose and McDonald (2005) found that locus of control relates to stress in parents of children with intellectual disabilities. Weiss (2002) also showed that mothers with hardy personalities cope better with raising children with an ASC, mental retardation, and typically developing children. Weiss (2002) found that personal factors foster adjustment to stress. The study specifically showed that mothers with hardy personalities were less prone to depression, anxiety and depersonalization (Weiss, 2002). The study also showed that cognitive appraisals play an important role in the experience of stress, as measured by a dimension of hardy personality. This agrees with the findings of the current study, showing that FIT Integrity played an important role in how both groups of mothers experienced parental and personal stress. These findings have important implications for the types of interventions used to promote resilience in different families. The results suggest that interventions targeting the development of strengths measured by FIT variables might have a positive impact on the ability of mothers to manage challenges in the parenting role.

### 4.7.3 FIT Science variables and family functioning

The study also aimed to retest the relationship between FIT variables and family functioning that was demonstrated in studies one and two. The study explored whether personal strengths were related, in both groups of mothers, to perceptions of overall family functioning. Additionally, the study attempted to further demonstrate that personal strengths significantly predict perceptions of general family functioning. Mothers in both groups reported similar perceptions of family functioning, with just over 48% of scores in each group falling in the clinical range of the general family functioning scale. This was somewhat surprising as many studies report elevated problems in family functioning in units with a member affected by an ASC. It was therefore expected that the majority of mothers in the ASC group would report clinically relevant problems in family functioning. The findings reported here do however concur with a study by Herring et al (2006) in which using the same measure of family functioning, the researchers showed that not all families with a member affected by an ASC report problems in family functioning.

For mothers of children with ASCs there were several significant correlations observed between perceptions of family functioning and scores on FIT variables. Furthermore, Behavioural Flexibility was also found to significantly account for just over 17% of variability in how mothers perceived the overall health of the family. Although children with ASCs are rigid in their behaviours and like routine in their daily life (Marcus & Stone, 1993), it appears that flexibility in mothers promotes coping with the stresses associated with parenting a child with a disability. Mothers who show flexibility in responding to different demands and constraints appear to tackle the negative impact of stresses on the health of the family.

A similar pattern of results was seen for mothers of typically developing children. In this group, cognitive strengths measured by FIT variables were significantly negatively correlated with perceptions of family functioning, together accounting for 24.2% of variability in family functioning scores. Furthermore, over group membership, FIT cognitive and behavioural strengths predicted how mothers

perceived family functioning. These findings support the proposed relationship between characteristics of people and personal and social outcomes (e.g. as suggested by Fletcher and Stead, 2000; Weiss, 2002).

### 4.7.4 FIT variables, family functioning and personal stress

Research suggests that problems in family functioning are related to depression and anxiety, particularly in families of children with disabilities (e.g. see Dyson, 1997). In this study, levels of depression in both groups of mothers were significantly positively correlated with problems in family functioning. The same pattern of results emerged for levels of anxiety for mothers of typically developing children. A consistent finding in research using FIT Science, and one confirmed throughout this thesis, is that FIT Integrity is related to levels of depression and anxiety. The study also supported the suggestion made earlier that FIT variables mediate the effect of family functioning on personal stress. This suggests that for mothers of children with ASCs, as well as mothers with typically developing children, FIT cognitive strengths alleviate the bidirectional relationship between family functioning and stress. The findings support the idea that there may be value in exploring how interventions targeting the development of personal strengths might help mothers in improving their perceptions in areas related to personal and family well being.

#### 4.7.5 FIT variables and family habits

In this study, for mothers of typically developing children, perceptions of effective and ineffective family habits were significantly related to cognitive FIT variables. There was a positive association between effective family habits and cognitive FIT variables, suggesting that mothers scoring high on FIT variables perceived more effective behaviours in family life. The reverse was true for the presence of ineffective habits. This suggests that personal strengths measured by FIT variables are related to behaving appropriately in situations involving the family. For mothers of children with ASCs, the results showed a trend in the same direction.

### 4.7.6 Strengths and limitations

A major strength of this study is that it was the first to consider the role of FIT variables in understanding differences in how mothers cope with parenting two distinct groups of children-children with an ASC, as well as children with typical development. Although other researchers have considered the role of personal factors in how mothers cope with caring for children with an ASC (e.g. Weiss, 2002), no studies have looked specifically at the role of personal strengths as defined and measured by FIT Science. As a cross-sectional study, this research has therefore provided novel work predicting why some mothers experience high levels of parenting, personal and family stress, whilst others do not. The differential factor may well be related to the FIT levels of parents, rather than simply the characteristics of the children being parented.

The study is however not without limitations. For both groups of mothers, a relatively small sample size was employed. This may have resulted in the study lacking statistical power, which is the likelihood of detecting significant results. However, mothers of young children and those especially of children with ASCs have high demands on their time and are therefore difficult populations to recruit. The relatively low non-response rate in both groups was therefore a strength of the study. In addition, withstanding the small sample size in each group, the study demonstrated an association between FIT personal strengths and family outcomes including family functioning, parenting and personal stress.

A further limitation relates to the under representation of mothers from minority groups, which influences the extent to which the results of the study can be generalized. Research elsewhere has shown that minority groups have more difficulty in accessing services for children with special health care needs (e.g. see Newacheck, Hung & Wright, 2002). In reference to minority groups parenting children with AScs, a report from the National Autistic Society has also shown that parents may be less aware of the right and relevant services available to them (Corbett & Perepa, 2007). This could imply that the stress in parents and families

from minority groups might be higher when raising a child with an ASC due to inadequate support. The extent to which the role of characteristics of mothers relates to parenting stress in minority groups is therefore unclear. However, parents are a very difficult group to recruit, and minority groups in particular pose a problem often due to language barriers and also because of cultural variations in how willing parents are to discuss family issues. The study has therefore provided further direction for research studies, which need to consider how personal factors influence outcomes in different groups of parents.

#### 4.7.7 Conclusions

The results of this study show that scores on FIT variables help explain differences in how mothers perceive their personal and family well being. Importantly, the study has shown that the mechanisms for coping are similar in different populations, albeit some groups are at increased risk of reporting problems across several domains. The study has also been successful in delineating the profile of a mother who is able to cope with the stresses associated with parenting. The results suggest that mothers who score high, particularly on cognitive FIT variables, perceive less problems in family functioning and report lower levels of parenting and personal stress. Furthermore, the study has shown that mothers characterized by these strengths, independent of the types of stressors in the environment, are more resilient.

The most important finding of this study is that despite ample research on the negative impact of children with ASCs on the family, stress is not inherent to having a child with a developmental delay. Factors within the parents are also important in determining their perceptions of parental, personal and family stress. Past research into family stress and disability has not paid due attention to this fact. This study suggests that interventions targeted at improving the personal resources of parents of children with ASCs might have a beneficial effect on perceptions across several domains. There may be value in exploring whether FIT Science offers a framework from which to intervene with parents to improve resilience. The following chapter

reports a study aimed at empirically testing this suggestion. The study tests whether or not developing personal strengths, measured by FIT variables, can improve the well being of mothers of children with ASCs. The study reports a randomized control trial of a FIT-Do Something Different intervention. Research suggests that this type of intervention is effective in helping with problems that have fairly intractable prognoses (e.g. see Hanson, 2008). The study reported is the first to empirically explore the usefulness of the FIT-Do Something Different intervention for helping mothers facing chronic stressors. The study also represents the first application of this type of intervention in the family context.

## Chapter 5

Study four: FIT Do Something Different- An intervention to develop personal strengths in mothers of children with Autistic Spectrum Conditions

#### 5.1. Introduction

This chapter reports a randomized control trial (RCT) of an intervention designed to develop personal strengths in mothers of children with ASCs. The intervention was aimed at increasing the personal strengths of mothers in the cognitive and behavioural areas of FIT Science. Mothers of children with ASCs were targeted for the RCT because they are known to experience high levels of parenting stress, which has an adverse effect on family life. In addition, results from study three suggested that this group might specifically benefit from interventions developing scores on FIT variables. Furthermore, study two showed that many adults with ASCs perceive their families as experiencing problems in functioning well. Taken together this suggests that families with a member on the autistic spectrum are in need of support in maintaining functioning and the well being of family members.

Before describing the development and findings of the RCT, the following review of the literature highlights what research has shown about promoting resilience in parents of children with ASCs. This will lead into why the FIT-Do Something Different (FIT-DSD) intervention reported here might be relevant for this group of mothers. To achieve this, it is necessary to have an understanding of the characteristics of children with ASCs and the demands their parents may have to cope with. The challenges associated with raising a child with an ASC were briefly discussed in study four. The literature reviewed here elaborates on the findings that were described to explore the full nature of stressors that mothers contend with. This will help delineate some of the shortcomings of previous attempts that have tried to support this unique group.

#### 5.2. Literature Review

## 5.2.1 Sources of stress when raising a child with an Autistic Spectrum Condition

Several studies have shown that ASCs are amongst the most stressful conditions for parents to cope with and are associated with multiple and complex sources of stress. As children, individuals with ASCs exhibit a range of challenging behaviours. In a review of interventions targeted at reducing challenging behaviours in children with ASCs, Horner, Carr, Strain, Todd & Reed (2002) highlighted areas of concern are self-injury, aggression and stereotypy (excessive repetition of movements, phrases etc). Many researchers have also tried to identify the most challenging characteristics associated with ASCs. Research by Sharpley, Bitsika & Efremidis (1997) suggests that the long-term nature of ASCs, coupled with a lack of acceptance of the condition by family members, the wider society, and inadequate support for parents contributes significantly to parenting stress. These findings agree with the consistent stress profile in parents of children with ASCs reported by Koegel et al (1992). Dunn, Burbine, Bowers & Tantleff- Dunn (2001) on the other hand found that the most stressful symptoms for parents relate to impairments in verbal communication, uneven cognitive functioning and problems in interacting with others. As adults, those affected by ASCs continue to experience trouble with living 'an ordinary life' due to difficulty in developing and maintaining meaningful relationships, finding employment, and living independently (Barnard et al, 2001). Parents of children with ASCs might therefore contend with many unique sources of stress throughout the course of the child's life cycle.

The persistent stress related to caring for a child with an ASC has also been associated with parent burnout, lack of self-confidence and self –esteem, the experience of emotions such as anger, guilt, frustration and resentment and high levels of depression and anxiety, particularly for mothers who often assume the role of primary care-givers (Gray & Holden, 1992; Holroyd & McArthur, 1976; Sharpley et al, 1997). Caring for a child with an ASC also places a great deal of strain on marital relationships with many couples reporting problems in marital adjustment

and thoughts of divorce (DeMyer, 1979). Research in the field of intellectual disabilities has also shown that families experience stress related to marital breakdown and difficulties faced in transitions within the child's life cycle (e.g. see Rhodes, 2003).

In addition, parents may experience strain related to time devoted to the child with an ASC, which results in other siblings feeling neglected (Morgan, 1988). The impact on siblings can exacerbate the stress experienced by parents where researchers have shown that having a sibling with an ASC often causes children concern about the future, resulting in them viewing their brother or sister as a burden (Bagenholm & Gillberg, 1991). In addition, parental reports suggest that siblings of children with ASCs display high levels of behaviour problems and less pro-social behaviour (Hastings, 2003). Lefkowitz, Crawford & Dewey (2007) also found that siblings of children with ASCs, when compared to siblings of typically developing children, were more likely to display behavioural and emotional problems and difficulties in social competence, thus adding to parental stress. Fathers in particular have been found to worry about the financial strain of caring for a child with an ASC (Rodrigue, Morgan & Geffken, 1992). Overall, research has clearly shown that as a challenge to the family, ASCs have the potential to impact several aspects of family life from interfamily relationships to problems related to the provision of family resources.

### **5.2.2 Family Resilience**

The way parents and other family members cope with their circumstances is also important. This is because, one fact, the significance of which often goes unnoticed is that many families do adapt successfully to caring for a child with an ASC. For example, research with siblings is mixed where some studies have shown that having a sibling with an ASC brings about positive outcomes such as healthy self-concept (Berger, 1980). In addition, siblings of children with ASCs often report less quarrelling and competition and greater admiration for their brother or sister who has been affected (Kaminsky & Dewey, 2001). Anecdotal evidence from parents also

suggests that raising a child with an ASC heightens empathy and acceptance for difference, as demonstrated in the following quote from a parent of a young girl with an ASC: 'Several positive things have resulted from Katie's autism...my personal experience with autism has given me much more visceral appreciation. When I see a person acting strangely in public, I no longer jump to judgment about how inappropriately he or she is acting, and I consider the very real possibility that she or he has a disability' (Ariel & Naseef, 2006, p.32). It is therefore important to understand factors that differentiate families who cope well with parenting a child with an ASC versus those who experience difficulties.

One factor may be the extent to which a child has been affected by an ASC. Parents of more severely affected children often report higher levels of family stress (Dunn et al, 2001). Another avenue of research has focused on exploring the role of coping strategies in resilience. This may be because models of family adaptation to stressful life events emphasise the role of coping strategies in promoting adjustment. For example, attempts at demonstrating the usefulness of the double ABCX model of family stress have shown that social support and family coping patterns are important in successful adjustment to ASCs (Bristol, 1987; Pakenham, Samios & Sofronoff, 2005). This suggests that family coping styles might influence how well units manage the stressors associated with ASCs, independent of how severely a child has been affected.

A wealth of literature has looked at the association between parental stress and coping styles in the context of ASCs. A consistent finding is that parents employing fewer emotion-focused coping strategies show better adjustment to ASCs, as do parents using positive reframing (Dunn et al, 2001; Hastings et al, 2005). Many studies have also highlighted the usefulness of social support in helping adaptation to ASCs (Luther, Canham & Young-Curteon, 2005; Weiss, 2002). Finally, there is some evidence to suggest that religious coping helps some parents (Tarakeshwar & Pargament, 2001).

Furthermore, Hastings et al (2005) found that active avoidance coping and denial were related to elevated stress and mental health problems in both mothers and fathers of pre-school and school aged children with ASCs. Hastings et al (2005) also found that religious coping, for their sample of parents, was not a salient factor in helping adaptation. Other researchers have shown that escape and distancing are related to higher levels of family stress (Sivberg, 2002).

Research of the nature discussed above suggests that the coping styles of parents are important in facilitating adjustment to raising children with ASCs. The studies suggest that promoting positive coping strategies such as acquiring social support might improve the experience of stress in parents of children with ASCs. However, very few, if any studies in the area of ASCs or intellectual disabilities have specifically focused on enhancing parental coping strategies. The support to parents in studies employing interventions has tended to focus on two areas. First, trying to reduce problem behaviours in the child in aim of promoting personal and family well being. Second, emphasis has been placed on skills training for parents for them to be able to understand their child's behaviour and actively engage in reshaping it. These types of interventions are not specifically directed at developing parental coping styles but might indirectly result in better coping and adaptation to looking after a child with an ASC.

# 5.2.3 Interventions aimed at reducing problem behaviours in children with Autistic Spectrum Conditions

Although perhaps one of the most defining features of ASCs and one that concerns many parents, research has shown that social dysfunction is responsive to intervention. A study by Thorp, Stahmer & Schreibman (1995) used pivotal response training -which works by motivating children with task related reinforcers- to demonstrate that young children with ASCs could be taught play, language and social skills. Dawson & Galpert (1990) also found that by having mothers, over the course of two weeks, engage in imitating their child in play for twenty minutes each day, researchers were able to enhance gazing towards the

mother's face and play behaviour (e.g. playing with novel toys). Kasari, Freeman & Paparella (2006) used an RCT design and found that when compared to a control group, children receiving interventions targeting joint attention or symbolic play improved in their ability to either initiate joint attention or to engage in more symbolic play with the mother. Eikeseth, Smith, Johr & Eldevik (2007) also examined the effectiveness of behavioural or eclectic training at 8 years of age in children who began receiving treatment at approximately 5.5 years. In both groups, children received treatment in a one-to-one setting for 28-29 hours before entering school. This reduced to between 18-16 hours when the child started attending school. In each case, treatment was carried out in the child's kindergarten and later the school setting. At follow-up, children receiving behavioural therapy showed less behaviours that clearly distinguished them from their peers, had increased levels of IQ, social, communication and adaptive functioning; although some benefits of eclectic training were also noted. Finally, Norris & Dattilo (1999) have demonstrated that social stories targeting problem behaviours in individual children can also be effective in bringing about behavioural change.

Although a comprehensive overview of the literature on interventions aimed at enhancing functioning in children with ASCs is beyond the scope of this review, what should be clear from the research discussed above is that children with ASCs are responsive to a wide range of interventions. However, many of these studies have employed very small sample sizes and therefore the extent to which the results generalize to other children is unclear. The study by Norris and Dattilo (1999), for example, involved one child with an ASC, whereas the sample size in the study by Thorp et al (1995) was three. Most importantly for this review, none of the above studies investigated whether interventions aimed at reducing difficult behaviours in children have a positive impact on parent levels of stress. There is however a strand of research that has specifically targeted parenting behaviours and investigated the effect of interventions with parents on family well being.

### 5.2.4 Interventions aimed at training parents

Research into helping parents cope with raising a child with an ASC has tended to rely on interventions using Behaviour Parent Training (BPT). BPT is often used with parents of children who display externalizing behaviours that are problematic such as impulsivity, inattention, aggression and non-compliance. BPT is thought to be the most effective means of changing parenting behaviours by using principles of social learning to help parents actively shape the behaviours of their child (Mah & Johnson, 2008). Although a number of BPT programmes have been developed, these generally emphasize parents monitoring their child's behaviour and giving clear and concise instructions and reinforcing positive child behaviours, whilst trying to extinguish negative behaviours (Mah & Johnson, 2008). As BPT is grounded in behavioural psychology, the focus is on bringing about observable changes in child and parenting behaviour (Mah & Johnson, 2008). Serketich & Dumas (1996) further state that BPT acknowledges the role of the parents in the development and maintenance of antisocial child behaviours. Behaviour is seen as learnt through the environment and continues due to reinforcement. As such, the goal of BPT programmes is to modify social contingencies so that children engage in positive behaviours for which they receive appropriate reinforcement (Serketich & Dumas. 1996).

There is much evidence to support the effectiveness of BPT in different groups of children, including children with ASCs. For example, Sofronoff & Farbotko (2002) trained parents in how to manage Asperger syndrome, which is a milder form of autism. The training was delivered either as a one- day workshop or six individual sessions in which parents were taught about what Asperger syndrome is and how to manage problem behaviours children exhibit. This study found that training delivered in both formats was effective in enhancing parental self-efficacy in the ability to deal with problem behaviours. The gains from the training were also present at three-month follow-up, suggesting that the training had at least short-term benefits for parents raising children with Asperger syndrome. Drew et al, (2002) have also presented findings from an RCT of a parent training intervention,

which focused on behavioural management and the development of early precursors of communicative and social skills in young children with ASCs. Like many BPT programmes, Drew et al (2002) incorporated the training into the child's daily routines such as at meal times and across different settings to achieve maximum generalization of changes. This study also found evidence to support the effectiveness of parent training in facilitating development in pre-school children with ASCs. In addition, researchers also measured parental stress in those receiving the parent training at baseline and follow-up. Although Drew et al (2002) do not discuss changes in parental stress other than to say that time 1 and follow up scores were highly correlated, there is some evidence to suggest that parent training may have reduced parental stress. Scores on the Parental Stress Inventory (Abidin, 1986) changed from 113.8 (*SD*=21.7) at baseline to 104.3 (*SD*=20) at follow-up for parents receiving training, when compared to a control group in which no change was observed.

Despite the potential value of training parents, not all parents see the benefits of it (Robbins, Dunlap & Plienis, 1991). Helm & Kozloff (1986) proposed that this is because parent training tends to focus on isolated areas, with little consideration of the broader issues families contend with. For example, studies might focus on developing parent abilities to manage early behaviour problems, whilst ignoring the problems parents might experience in the marital relationship. Few studies have also directly measured the effect of intervention on parenting and personal stress, or commented in great detail on the personal benefits parents receive from intervention (e.g. changes in depression, anxiety, parental stress and coping behaviours). This is true of many studies aimed at improving both parental ability to manage ASCs, and those working on developing child behaviours. Furthermore, in looking at the effectiveness of interventions in this field, RCT designs are rare (Drew et al, 2002). This makes it even more difficult to be sure that the observed benefits are due to the intervention, rather than confounding variables or the general demand characteristics of taking part in an intervention.

There are however more fundamental problems with using BPT to address stress in parents of children with ASCs. First, the requirement of parents to invest time to either attend parent training sessions, or to be trained within their home environment. Mothers of children with ASCs have high demands on their time, including the care of the child with an ASC, siblings, employment and other life commitments. The feasibility of mothers taking time out to engage with BPT is therefore questionable. Assuming time was not an issue, there are problems related to making such training widely available and accessible by the growing number of parents of children with ASCs from different geographic, educational and ethnic backgrounds. Training programmes would also need to suit the needs of parents at different points of their child's life cycle. An intervention programme to help parents manage their stress therefore needs to be both time and cost effective and potentially accessible in terms of its content by parents from different backgrounds and with different needs.

## 5.3. The Study

Many parents do show resilience in caring for a child with an ASC. What is needed is further understanding of the wide variation of effects reported by different parents. This will help inform what it is about a parent in particular that makes him or her more likely to be able to manage the stresses associated with raising a child with an ASC, in comparison to a parent who fails to cope well. The research above has suggested that the degree to which a child is affected by an ASC has a large role to play and that coping strategies and parenting behaviours are also important. However, more importantly, research reported elsewhere in this thesis suggests that the personal strengths of parents, as defined by FIT Science, plays a significant role in the experience of parental, personal and family stress. Evidence presented in study three of this thesis has shown that stress in these areas can be predicted by a mother's own strengths in the cognitive areas of FIT Science, and this is independent of child characteristics. This is important because it suggests that characteristics of parents and characteristics of children jointly affect levels of parent and family stress. In addition, this finding opens up a different avenue for

intervention with parents of children with ASCs, and one that might overcome some of the shortcoming of BPT.

The focus of this chapter is on describing the development and results of an RCT of the FIT-Do Something Different (FIT-DSD) intervention, which was designed to promote well being in mothers of children with ASCs. The intervention was designed to be accessible by mothers at different stages of their child's life cycle and to be both cost and time efficient. The FIT-DSD intervention was designed to expand everyday behaviours in mothers of children with ASCs. This is because Fletcher and colleagues suggest that getting people to change their natural ways of doing things and disrupting their behavioural habits might bring about deeper, positive changes in how people think about different situations. These changes can be measured using The FIT Profiler and their benefits result in observable changes in parent and family well being. The results of study three also support the idea that developing FIT strengths in mothers of children with ASCs might have a positive effect on maternal levels of parenting and personal stress, and also perceptions of family functioning.

### **5.3.1 Hypotheses**

Studies one, two and three in this thesis have examined the association between scores on FIT variables and how people perceive their family functioning and family habits, and levels of parenting and personal stress. The findings of these studies have suggested that developing FIT strengths might be associated with a number of benefits for individuals. This study compares a one-month FIT-DSD intervention to a control condition for mothers of children with ASCs. It is predicted that mothers who receive the FIT-DSD intervention will, at follow-up report:

- 1. Significantly greater improvements in parenting stress.
- 2. Significantly greater improvements in levels of depression and anxiety.
- 3. Significantly greater improvements in how they perceive their family functioning.
- 4. Significantly more effective family habits, and significantly fewer ineffective family habits.
- 5. Significantly greater improvements in personal strengths, as measured by scores on FIT variables.
- 6. The development of significantly more effective coping strategies that are relevant to the family.
- 7. Significantly more positive perceptions on their relationship with their spouse or partner.

#### 5.4.Method

## **5.4.1 Participants**

Twenty-six mothers of children with ASCs were recruited to take part in this study. Mothers were recruited via three parent support groups and the Autism Advisory Service, both in Hertfordshire. Mothers recruited via support groups received an email with information about the study and were asked to contact the researcher if they would like to take part in the research. Mothers recruited via the Autism Advisory Service received an information sheet about the study from their 'Nursery Nurse'- a member of the service who provides social interaction opportunities within the home for children under 5 affected by ASCs. Twenty- six mothers responded stating that they would be interested in taking part in the research. Mothers were randomly allocated to the FIT-DSD intervention group, or a wait list control group. Two mothers in the control group did not complete the post-test and their data was therefore excluded from the study, leaving an overall sample of 24 mothers. The two mothers that failed to complete the study did not differ from the sample of mothers in terms of their demographics.

The 24 mothers who completed the study had a mean age of 40 years (M=40.46, SD=6.54), all were White British and had attained a high school education. The modal level of education was an undergraduate degree (29.2%). Fifty-four percent of mothers were unemployed or homemakers. Eighteen mothers were married, 3 were separated or divorced, 2 were single parents and one mother was unmarried but living with the father of her child with an ASC.

The children involved in this study had a mean age of seven and a half years (M=7.71, SD=2.85, age range 3-12 years), 20 were male and 4 were female. An inclusion criterion for this study was that a professional had diagnosed the child with an ASC using criteria from the Diagnostic and Statistical Manual of Mental Disorders  $4^{\text{th}}$  edition. Mothers also completed The Childhood Autism Rating Scale (Schopler et al, 1988) to verify diagnosis. The mean score for children on the Childhood Autism Rating Scale was 37.23 (SD=5.81). All children fell within the autistic range of the scale with 12 in the mild-moderate category and 12 in the severe autism range of the scale.

#### **5.4.2 Procedure**

After contacting the researcher and giving consent to take part in the study, mothers were randomly allocated to either the FIT-DSD intervention group (n=13) or control group (n=11). Random allocation was achieved using a computerized random number generator. The researcher co-ordinating the random allocation was blind to the study. Mothers forming the control group believed they would be receiving an intervention after 4 weeks during which they took part in the study and were indeed provided the intervention resources on completion of the study. The FIT-DSD intervention group believed that they were taking part in a study comparing the effect of different types of interventions on maternal well being and that as part of the research, depending on which group they were allocated to, they may receive a 'placebo' intervention. The latter was intended to minimize the likelihood of effects being due to mothers believing that they are receiving a 'true' intervention to help manage their stress rather than the benefits of the intervention itself per se.

After allocating mothers into one of the study conditions, all participants were mailed a questionnaire pack to complete at outset (one week before entering the study). The same questionnaire pack was also completed at follow-up (within a week of having taken part in the study for 30 days). Mothers in the FIT-DSD intervention group were visited in their home by the researcher and given materials and had the intervention explained to them. The first set of materials was a pack of 40 FIT 'expander' cards, each containing an activity to expand day-to-day experiences. The instruction was to attempt one card everyday over the coming month. Mothers were free to choose which cards they attempted but were asked to avoid repeating cards. Examples of tasks included 'do your shopping at a different supermarket' and 'go into a shop and try on three items of clothing you wouldn't *dream of wearing'*. The expander cards were adapted from an existing DSD intervention reported by Fletcher et al (2005). The second set of materials comprised a set of 50 FIT 'disrupter' cards, each with tasks that could be done quickly to help diffuse feelings of stress. Mothers were instructed to use these cards when feeling stressed in situations involving their child to allow them a quick 'timeout'. Examples included 'estimate the number of steps to a place in the room you're in and walk there' and 'place your hands in as many different positions as you can in the *next minute*'. The disrupter cards were developed through discussion with parents at local support groups about the strategies they find effective for dealing with stressful situations. Additional tasks were also developed by the research team that were deemed suitable for the target population. Although mothers were provided with two types of resources, the general aim of both sets of cards was to break daily habits and to expand natural ways of doing things and managing situations. As such, for the intervention, the emphasis was not on which types of cards the mothers used the most, but the general number of cards they used over the course of the intervention. Mothers were provided with a calendar to record the overall number of cards they attempted each day. Mothers took part in the FIT-DSD intervention group or wait list control group for 30 days, after which they completed the questionnaire pack again. Mothers in the FIT-DSD intervention group attempted on

average 37 tasks (*SD*=15.4) (not differentiating between expander and disrupter cards) over the course of the intervention.

## **5.4.3 Questionnaire Measures**

The questionnaire pack completed at outset and following the intervention period consisted of the Childhood Autism Rating Scale (CARS), the Parenting Stress Index-Short Form (PSI-SF), the general functioning scale from the Family Assessment Device (FAD), the Family Habit Assessment Tool (FHAT), the Family Crisis Oriented Personal Evaluation Scales (FCOPES), the Relationship Assessment Scale (RAS), and The FIT Profiler. At outset, participants were also asked demographic questions about their age, education, ethnicity, marital status and occupation. Details on the Childhood Autism Rating Scale, Parenting Stress Index-Short Form, Family Assessment Device, Family Habit Assessment Tool and The FIT Profiler can be found elsewhere within this thesis (see study one and study three).

### 5.4.3.1 The Family Crisis Oriented Personal Evaluation Scales

The Family Crisis Oriented Personal Evaluation Scales (FCOPES) (McCubbin, Olson & Larsen, 1991) is a 30-item measure of problem solving strategies employed by families facing difficult situations. The FCOPES has five subscales: acquiring social support, reframing, seeking spiritual support, mobilizing the family to acquire and accept help and passive appraisal. A total coping score is also included. Items are rated using a 5-point scale ranging from 1 'strongly disagree' to 5 'strongly agree'. Higher scores on subscales of the scale reflect the use of more varied problem solving strategies in times of crisis. Total scores on the Family Crisis Oriented Personal Evaluation Scales range from 30 to 150. As a measure of family coping, the scale has good internal consistency and reliability (McCubbin et al, 1991). Although many self-report measures of coping behaviours have been developed, the Family Crisis Oriented Personal Evaluation Scales was chosen for use in this study because it has been previously used with parents of children with ASCs (e.g. see Twoy, Connolly & Novak, 2007). Data on coping behaviours seen in mothers involved in

this study could therefore be compared to previous research to note particular similarities or differences in coping styles.

### 5.4.3.2 The Relationship Assessment Scale

The Relationship Assessment Scale (RAS) (Hendrick, 1988) is a 7-item measure of satisfaction in a romantic relationship. Items are rated on a 5-point scale ranging from 'low satisfaction' to 'high satisfaction'. Example items from the scale include 'how well has your partner met your needs?' and 'to what extent has your relationship met your original expectations'. Two items of the scale are reverse scored, yielding a maximum satisfaction score of 27, with the lowest score for relationship satisfaction being 15. The Relationship Assessment Scale has demonstrated sound psychometric properties and also correlates well with other established measures of relationship satisfaction (Hendrick, 1988; Hendrick, Dicke & Hendrick, 1998). The Relationship Assessment Scale was chosen for use in this study because it allows for assessment of satisfaction in romantic and not marital relationships. It was anticipated that not all mothers would be married to their partner, or living with their child's biological father. Therefore, the Relationship Assessment Scale may be more appropriate than a measure specific to those in marital relationships.

#### 5.4.3.3 Other Materials

Mothers received an information sheet about the study, a consent form and were asked to contact the researcher if they were interested in taking part in the study. The information sheet and consent form gave details about what taking part in the study involved and stated that mothers could withdraw from taking part at any time. Mothers were either emailed these materials via their support group administrator, or given them via a nursery nurse from the Autism Advisory service.

Mothers allocated to the FIT-DSD intervention group received two sets of FIT-DSD materials- expander and disrupter cards. Mothers also received a calendar to record details of how many cards they attempted over the course of the study. Finally, all participants received a de-briefing sheet at the end of the study restating the study

aims and providing details of the services offered by the National Autistic Society to help them cope with raising a child with an ASC.

#### 5.5. Results

## 5.5.1 Controlling for between group differences

As this was an RCT of the FIT-DSD intervention, it was possible that random allocation may have led to between group differences that could affect the results of the study e.g. maternal level of education or marital status, degree to which a child has been affected by an ASC. Before comparing groups at outset and follow-up, Chi-Square Analysis was used to establish the nature of differences between groups in demographic variables. Chi-Square Analysis confirmed no differences between groups at outset in marital status ( $X^2(3, N=24) = 1.39$ , p = 0.71, two-tailed), highest educational qualification achieved ( $X^2(5, N=24) = 3.21$ , p = 0.67, two-tailed) and employment status ( $X^2(6, N=24) = 4.95$ , p = 0.55, two-tailed). Independent samples t-tests also confirmed there were no differences in the mean age of mothers (t(19.91) = -0.84, p = 0.41, two-tailed) and scores on the Childhood Autism Rating Scale of children involved in the study (t(22) = 0.73, p = 0.47, two-tailed). These results indicated that the findings of the study are unlikely to be due to pre-existing differences and can be attributed with confidence to the intervention.

#### 5.5.2 Comparing groups at outset

Data were analysed using independent samples t-tests to see if the FIT-DSD intervention and control group differed at outset on measures of parental stress, family functioning, family habits, coping strategies, relationship satisfaction and scores on FIT variables. Descriptive statistics related to these measures at outset are presented in tables 5.1, 5.2 and 5.3.

#### 5.5.2.1 Parenting Stress

Table 5.1 shows that mothers in both the control and FIT-DSD intervention group were experiencing high levels of total parenting stress. The mean total parenting stress score in the control group was 114.72 (*SD*= 18.82) and the mean was 109.84 (*SD*=12.04) in the FIT-DSD intervention group. Abidin (1990) suggests that raw scores in total parenting stress over the cut off of 90 reflect parents experiencing clinically relevant levels of stress. The majority of mothers in each group scored in the clinical range for parenting stress. Only one mother in each group scored in the normal range for total parenting stress. Mothers also scored high on subscales of the Parenting Stress Index- Short Form, given that scale scores range from 12-60. Mothers in the control and FIT-DSD intervention group reported most stress in relation to difficult child behaviours.

Table 5.1 also displays the results of independent samples t-tests that were carried out with the aim of comparing whether the parental stress experienced by the FIT-DSD intervention and control group differed at the start of the study. Analyses that were reported in section 5.5.1 showed that mothers in both groups were comparable in terms of the degree to which their children had been affected by an ASC (i.e. scores on the Childhood Autism Rating Scale were not significantly different between groups). The results of the independent samples t-tests using group as the independent variable, and each subscale score from the Parenting Stress Index-Short Form as the dependent variable, also confirmed that mothers in both groups were experiencing similar levels of parental stress.

**Table 5.1.** Group means (SD) at outset from the Parenting Stress Index-SF (PSI-SF)

	FIT-DSD (n=13) pre-intervention	Control (n=11) pre-intervention	t-value (df=22)	Significance (two-tailed)
PSI-SF:				
Total Stress	109.84 (12.04)	114.72 (18.82)	.76	.45
Parental Distress	34.69 (5.15)	36.09 (7.86)	.52	.60
P-CDI	32.84 (6.09)	34.18 (7.15)	.49	.62
Difficult Child	42.30 (6.93)	44.45 (7.92)	.70	.48

*P-CDI*= parent-child dysfunctional interaction. The total parenting stress score ranges from 36-180, with subscale scores ranging from 12-60.

### 5.5.2.2 Family Functioning

The mean score for both comparison groups in general family functioning is shown in table 5.2. The mean of the control group is higher than the mean of the FIT-DSD intervention group, which suggests that mothers in the control group perceived their family functioning as being more problematic. Ryan et al (2005) suggest that scores above 2 in general family functioning indicate a family experiencing clinically significant problems. Just over 81% of mothers in the control group scored in the clinical range of the general family functioning scale, whereas only 38% of mothers in the FIT-DSD intervention group perceived their family functioning within the clinical range. An independent samples t-test using group as the independent and the general family functioning score as the dependent variable confirmed that mothers in the control group reported significantly more problems in family functioning on entering the study (t(22) = 3.52, p < 0.01, two-tailed).

#### 5.5.2.3 Family Habits

The mean family habits scores for mothers in the FIT-DSD intervention and control group are shown in table 5.2. The group means show that although the control group experienced more problems in general family functioning, in terms of family habits, this group reports marginally more effective family behaviours. The mean score of the control group for effective family habits was 6.31(SD=.66) and the mean was 6.29 (SD=.91) in the FIT-DSD intervention group. It should however be noted that both groups score high on the effective family habits subscale of the Family Habit Assessment Tool. This is because the range of scores on this scale is between 2 and 8, with high scores in the effective and ineffective domains presenting different types of entrenched family behaviours. In reference to ineffective family habits, the control group again scored higher than the FIT-DSD intervention group. The mean number of ineffective family habits reported by the control group was 5.01 (SD=.67). The mean in the FIT-DSD intervention group was 4.50 (SD=.99). Differences at outset between groups in family habits were compared using independent samples t-tests, the results of which are given in table 5.2. The t-tests failed to reach significance, showing that overall, the groups were comparable in reported levels of effective and infective family habits.

**Table 5.2.** Group means (SD) at outset from the Family Assessment Device (FAD), Family Habit Assessment Tool (FHAT), Family Crisis Oriented Personal Evaluation Scales (FCOPES) and the Relationship Assessment Scale (RAS)

	FIT-DSD (n=13) pre-intervention	Control (n=11) pre-intervention	t-value (df=22)	Significance
FAD: General Family Functioning FHAT:	1.74 (.36)	2.22(.29)	3.52	.002**
Effective Habits Ineffective habits <i>FCOPES:</i>	6.29 (.91)	6.31 (.66)	.07	.94
	4.50 (.99)	5.01 (.67)	1.45	.16
Total	97.23 (22.42)	91.45 (12.54)	.75	.45
Reframing	31.30 (7.09)	29.00 (3.43)	.98	.33
Acquiring social support	26.46 (8.43)	26.45 (6.89)	.002	.99
Passive appraisal Mobilizing the family Seeking spiritual support	15.76 (3.83)	13.81 (3.15)	1.34	.19
	13.76 (3.81)	13.36 (2.90)	.28	.77
	7.38 (5.57)	6.45 (4.03)	.46	.65
RAS	22.84 (8.6)	18.00 (10.78)	1.22	.23

<sup>\*\*</sup>Significant at p < 0.01, two-tailed.

High scores on FHAT & FCOPES subscales and on the RAS indicate the use of more entrenched family habits, the use of varied coping strategies and greater satisfaction in a romantic relationship. Scores on the general family functioning scale from the FAD above 2 reflect families experiencing clinically relevant problems in functioning.

#### 5.5.2.4 Coping Strategies

Table 5.2 also shows the mean scale scores of mothers in areas of the Family Crisis Oriented Personal Evaluation Scales (FCOPES), which measures family coping behaviours. Scores in total coping strategies range from 30 to 150, with higher scores indicating the use of more varied ways of coping with family problems. Mothers in both comparison groups appeared to use varied ways of coping at outset. The total coping scores are relatively high in both groups when compared to the minimum total score of 30. The mean total coping score of the FIT-DSD intervention group was 97.23 (*SD*=22.42), which was higher than that of the control group in which the mean was 91.45 (*SD*=12.54). There is also a similar pattern between groups as to the types of strategies relied on most, with reframing problems being the most common means of coping, and seeking spiritual support being the least used strategy to cope with family problems.

Independent samples t-test were carried out to compare groups at outset in the use of coping strategies, the results of which are shown in table 5.2. The independent samples t-tests showed that despite some differences in the descriptive data, the control and FIT-DSD intervention groups did not differ in the strategies used to deal with family problems.

#### 5.5.2.5 Relationship Satisfaction

Table 5.2 shows the relationship satisfaction score of mothers in both groups. Scores of the Relationship Assessment Scale range from 15 to 27, with a higher score indicating more satisfaction in a romantic relationship. On entering the study, the group means suggest that mothers in the FIT-DSD intervention group were experiencing more satisfaction in their romantic relationship (M=22.84, SD=8.6) than mothers in the control group (M=18.00, SD=10.78). An independent samples t-test using group as the independent and the score on the Relationship Assessment Scale as the dependent variable however showed that mothers in both groups were comparable in their level of relationship satisfaction (t(22) = 1.22, p = 0.23, two-tailed).

#### 5.5.2.6 Personal Stress

Table 5.3 shows group mean scores in depression and anxiety for mothers in the FIT-DSD intervention and control group. Scores on each of the subscales of the Thoughts and Feelings Scale measuring depression and anxiety range from 4 to 16, with high scores indicating higher levels of stress. Mothers in both comparison groups appear to be experiencing feelings of both depression and anxiety. The mean level of depression reported in the FIT-DSD and control groups was 9.46 (SD=2.50) and 10.72 (SD= 2.53) respective. In the FIT-DSD intervention group, just over 61% of mothers reported normal levels of depression. One mother also scored in the clinical range for depression. In the control group, just over 36% of mothers scored in the normal range for depression and three mothers scored in the clinical range of the depression scale. The mean anxiety score reported by mothers in the FIT-DSD intervention group was 10.23 (SD=2.42) and the mean of the control group was 12.18 (*SD*= 3.15). Just over 53% of mothers in the FIT-DSD intervention group scored in the normal range for anxiety and three mothers also scored in the clinical range for anxiety. In the control group, 36% of mothers scored in the normal range for anxiety and 54% scored in the clinical range.

Table 5.3 also displays the results of the independent samples t-tests that were carried out comparing groups in their levels of depression and anxiety. The results of the t-test showed that mothers allocated to the FIT-DSD intervention group did not differ from mothers in the control group in their levels of depression and anxiety. This suggests that mothers who took part in this study were comparable on entering the study in terms of the types of children they were raising (scores on the Childhood Autism Rating Scale) and both their levels of parenting and personal stress.

#### 5.5.2.7 FIT Science variables

The final results compared differences on FIT variables on entering the study. Table 5.3 shows group means in the cognitive areas of FIT Science and in Behavioural Flexibility. The general patterns of results across groups appears to be consistent in that mothers report the greatest level of cognitive strength in the Constancy of Ethics and the most problematic area is reflected in low levels of Fearlessness. Mothers in both groups also report fairly low levels of Behavioural Flexibility, given that this score ranges from a 0 to 100, with higher scores indicating a wider repertoire of behaviours . The mean group scores for Behavioural Flexibility were 22.18 (SD=12.98) in the FIT-DSD intervention group and 18.06 (SD=13.19) in the control group.

Independent samples t-tests were carried out to compare mothers in both groups in their levels of personal strengths on entering the study. These results are shown in table 5.3 and demonstrate that mothers who took part in this study did not differ in their profiles of personal strengths on entering the study. This is important because it indicates that any gains of the FIT-DSD intervention cannot be attributed to some mothers being more susceptible to benefits of intervention e.g. because they were more flexible and able to engage more readily with the intervention materials.

Table 5.3. Group means (SD) at outset from The FIT Profiler

	FIT-DSD (n=13) pre-intervention	Control (n=11) pre- intervention	t-value (df=22)	Significance (two-tailed)
The FIT Profiler:				
Integrity	62.67 (10.98)	57.70 (9.65)	1.16	.25
Self-responsibility	6.44 (1.54)	6.18 (1.00)	.47	.64
Awareness	6.54 (.92)	6.30 (1.15)	.56	.57
Ethics	8.19 (1.25)	7.37 (1.35)	1.54	.13
Balance	5.09 (1.33)	5.06 (.67)	.06	.94
Fearlessness	5.08 (2.36)	3.94 (2.12)	1.23	.23
Behavioural Flexibility	21.18 (12.98)	18.06 (13.19)	.58	.56
Depression	9.46 (2.50)	10.72 (2.53)	1.22	.23
Anxiety	10.23 (2.42)	12.18 (3.15)	1.71	.10

Scores in the Constancies range from 1-10 and in Behavioural Flexibility from 0-100. Higher scores indicate greater levels of personal strengths. Scores in depression and anxiety range from 4-16, with higher scores indicating more psychological distress.

## 5.5.2.8 Discussion of data analysis comparing groups at outset

The results in sections 5.5.1 and 5.5.2 comparing the FIT-DSD intervention and wait list control group on entering the study suggest that random allocation to the study conditions should not confound the results at follow-up. This is because mothers in both groups were comparable on a range of demographic variables, including age, ethnicity, occupation and marital status. Mothers were also parenting children affected by comparable degrees of autism, experienced similar levels of parenting and personal stress, reported the presence of a similar level of effective and ineffective family habits, used comparable styles of coping with family problems, and reported no differences in satisfaction in romantic relationships. Finally, mothers were also comparable in their personal strengths and therefore in their likelihood of seeing similar gains from the intervention. Mothers in the control group did however report significantly more problems in family functioning. This is despite no apparent differences across other variables measured by the study.

## 5.5.3 Data Analysis at follow-up

Apart from scores on the general family functioning scale of the Family Assessment Device, the FIT-DSD intervention group did not differ significantly from the control group on dependent variables on entering the study. However, tables 5.1 to 5.3 show that there were some non-significant differences between group means on study variables. To minimise Type 2 errors, it was decided to be safer to do repeated measures t-tests to determine whether either of the group scores on the key dependent variables changed over time. For depression and anxiety scores this would seem a particularly sensible approach since it is known that affect scores are likely to reduce with time from higher levels without intervention (e.g. see Kirsch, Deacon, Huedo-Medina, Scoboria, Moore et al, 2008). The results presented at follow-up are split into two sections; the first exploring changes over the course of the study in the wait list control group, and the second exploring changes in study variables for the FIT-DSD intervention group.

## 5.5.3.1 Follow-up analysis of the control group

### 5.5.3.1.1 Parenting Stress

Table 5.4 displays means for the control group from outset and follow-up from the Parenting Stress Index-Short Form. The mean subscale scores and the total parenting stress score within the control group does not appear to have changed over the course of the study. This was confirmed in the results of paired samples t-tests also shown in table 5.4. This suggests that parental stress in mothers of children with ASCs, without intervention, is relatively high and stable, at least in the short-term.

**Table 5.4.** Control group means (SD) at outset and follow-up from the Parenting Stress Index-SF (PSI-SF)

Control group (n= 11)	Pre-intervention	re-intervention Follow-up		Significance (two-tailed)
PSI-SF:				
Total Stress	114.72 (18.82)	114.90(18.74)	.03	.97
Parental Distress	36.09 (7.86)	34.90 (6.42)	.70	.50
P-CDI	34.18 (7.15)	34.72 (6.61)	.24	.80
Difficult Child	44.45 (7.92)	45.27 (7.82)	.48	.63

*P-CDI*= parent-child dysfunctional interaction.

### 5.5.3.1.2 Family Functioning

Table 5.5 displays the mean score for the control group from outset to follow-up on the general family functioning scale of the Family Assessment Device. The mean of the control group at outset was above the suggested clinical cut-off score of 2 and over 81% of mothers scored in the clinical range of the general family functioning scale. At follow-up, the group mean remained above 2, suggesting that problems in family functioning remained stable in this group over the short-term. The results of a repeated measures t-test confirmed this (t(10) = .35, p = 0.73, two-tailed,).

### 5.5.3.1.3 Family Habits

Little change was seen in the control group from outset to follow-up for scores on the Family Habit Assessment Tool. The mean level of effective family habits reported went from 6.31 (SD=.66) at outset to 6.27 (SD=.62) at follow-up. No change was seen in reports of ineffective family habits. Two repeated measures t-tests showed that without intervention, the level of both effective and ineffective habits in family life remained consistent.

**Table 5.5.** Control group means (SD) at outset and follow-up from the Family Assessment Device (FAD), Family Habit Assessment Tool (FHAT), Family Crisis Oriented Personal Evaluation Scales (FCOPES) and the Relationship Assessment Scale (RAS)

Control Group (n= 11)	Pre-intervention	Follow-up	t-value (df=22)	Significance (two-tailed)
FAD:				
General Family Functioning	2.22 (.29)	2.20 (.24)	.35	.73
FHAT:				
Effective Habits	6.31 (0.66)	6.27 (.65)	1.00	.34
Ineffective habits	5.01 (0.67)	5.00 (.62)	.43	.67
FCOPES:				
Total	91.45 (12.54)	92.36 (10.00)	.32	.75
Reframing	29.00 (3.43)	29.09 (3.30)	.16	.87
Acquiring social support	26.45 (6.89)	25.81 (6.25)	.48	.63
Passive appraisal	13.81 (3.15)	15.09 (1.81)	1.81	.10
Mobilizing the family	13.36 (2.90)	13.63 (2.69)	.24	.80
Seeking spiritual support	6.45 (4.03)	6.18 (3.60)	.67	.51
RAS	18.00 (10.78)	19.09 (11.97)	1.32	.21

### 5.5.3.1.4 Coping Strategies

Table 5.5 also shows data from the Family Crisis Oriented Personal Evaluation Scales (FCOPES), which measure coping strategies. The control group means at outset and follow-up show little change in the total number of coping strategies employed by mothers in this group. In addition, over the course of the study, little change was noted in the different types of strategies mothers used to cope with problems relevant to the family. The use of social support seems to have decreased slightly, changing from a scale mean of 26.45 (SD=6.89) at outset to a mean of 25.81 (SD=6.25) at follow-up. The use of passive appraisal also changed from a scale mean of 13.81 (SD=3.15) at outset to a mean of 15.09 (SD=1.81) at follow-up. Paired samples t-tests however confirmed that the observed variations in use of coping strategies were non significant.

### 5.5.3.1.5 Relationship Satisfaction

The final results presented in table 5.5 relate to data from the Relationship Assessment Scale (RAS), measuring satisfaction in a romantic relationship. The group mean score for satisfaction changed from  $18.00 \ (SD=10.78)$  at outset to  $19.09 \ (SD=11.97)$  at follow-up. At the same time, data shows deviation around the group mean also increased. A paired samples t-test confirmed that over the course of the study, there was no change in relationship satisfaction in the control group (t(10) = 1.32,  $p = 0.21 \ two$ -tailed).

#### 5.5.3.1.6 Personal Stress

Table 5.6 displays mean scores in depression and anxiety for mothers in the control group at outset and follow-up. For both depression and anxiety, mean group scores are marginally lower at follow-up. There was also some change in the clinical significance of the levels of depression and anxiety reported. For example, at outset, just over 54% of mothers scored in the clinical range for anxiety. At follow-up, 36.4% of mothers scored in the clinical range for anxiety and 36.4% also scored in the marginal range. For depression, there were also more mothers at follow-up scoring within the normal range (change from 36.4% at outset to 54.5% at follow-

up), although there was no change in the number of mothers reporting clinical levels of depression. The repeated measures t-tests also reported in table 5.6 however show that changes in levels of depression and anxiety from outset to follow-up were not statistically significant, although there may have been slight changes in the clinical significance of the symptoms mothers reported.

**Table 5.6.** Control group means (SD) at outset and follow-up from The FIT Profiler

Control Group (n=11)	Pre-intervention	Follow-up t-value (df=10)		Significance (two-tailed)
The FIT Profiler:				
Integrity	57.70 (9.65)	56.20 (9.41)	.99	.34
Self-responsibility	6.18 (1.00)	5.96 (.78)	.77	.45
Awareness	6.30 (1.15)	6.30 (1.05)	.00	1.00
Conscience	7.37 (1.35)	7.40 (1.67)	.13	.89
Balance	5.06 (0.67)	4.49 (.87)	3.02	.01*
Fearlessness	3.94 (2.12)	3.93 (1.88)	.00	1.00
Behavioural Flexibility	18.06 (13.19)	25.45 (14.51)	1.70	.12
Depression	10.72 (2.53)	10.54 (2.65)	.48	.64
Anxiety	12.18 (3.15)	11.81 (2.75)	.31	.76

<sup>\*</sup> Significant at p < 0.05, two-tailed

#### 5.5.3.1.7 FIT Science variables

Table 5.6 shows how mothers in the control group scored on FIT Science variables at outset and follow-up. The means at outset and follow-up suggest that there is some change in how mothers scored on FIT variables. For example, Behavioural Flexibility scores increased from a mean of 18.06 (SD=13.19) at outset to a mean of 25.45 (SD=14.51) at follow-up. At the same time, deviation around the group mean also changed from 13.19 to 14.51. In addition, mothers reported less Balance at follow-up than at outset. The group mean for balance was 5.06 (SD=.87) at outset and 4.49 (SD=.87) at follow-up. This suggests less ability in prioritising different areas of life. Paired samples t-tests were carried out with the aim of exploring any changes in how mothers in the control group scored on FIT variables. The results of the t-tests are shown in table 5.6 and showed that mothers scored significantly lower in the Constancy of Balance at follow-up (t(10) = 3.02, p = 0.01, two-tailed).

Scores in personal strengths related to other areas of FIT Science did not change significantly from outset to follow-up.

5.5.3.1.8 Discussion of data analysis from outset to follow-up in the control group

Data presented in section 5.5.3.1 shows that over the course of this study, there was some change in the mean scores on scales from the Parenting Stress Index-Short

Form, Family Assessment Device, Family Habit Assessment Tool, Family Crisis

Oriented Personal Evaluation Scales, Relationship Assessment Tool and The FIT

Profiler within the control group. In the main, these changes failed to reach significance. Overall, the data suggests that without intervention, mothers in the control group did not improve in any measures of personal and family well being.

## 5.5.3.2 Follow-up analysis of the FIT-DSD intervention group 5.5.3.2.1 Parenting Stress

Table 5.7 displays means for the FIT-DSD intervention group from outset and follow-up from the Parenting Stress Index-Short Form. The descriptive statistics in table 5.7 suggest that after the intervention period, mothers in this group reported lower levels of total parental stress and less stress in the areas measured by the Parenting Stress Index-Short Form. The mean total stress score was 109.84 (*SD*=12.04) at outset, with the range of scores being 84 to 131. At follow-up, the mean total parenting stress score for this group was 97.00 (*SD*=13.43). The range of scores was now between 75 and 120. Three mothers now scored in the normal range for total parenting stress. Before the intervention, only one mother scored in the normal range for total parenting stress. A similar pattern of results is seen when examining the pre and post intervention scores on subscales of the Parenting-Stress Index-Short Form.

Table 5.7 also displays the results of repeated measures t-tests that were carried out to examine whether the FIT-DSD intervention reduced parental stress in mothers. The results of the paired comparisons show that there was a significant reduction in overall parental stress and stress in subscales of parental stress for mothers after having taken part in the FIT-DSD intervention. Table 5.7 also shows that for total parental stress and for the parent-child dysfunctional interaction subscale, the FIT-DSD intervention had a large effect on reducing levels of stress. A moderate effect of intervention was noted for the parental distress and difficult child subscales. Using Cohen's d, effect sizes of .2, .5 and .8 correspond to small, medium and large effect sizes respectively (Rosenthal, Rosnow & Rubin, 2000). Overall, the results suggest that the FIT-DSD intervention had a positive effect on parental stress. Although the mean total parental stress score for the group remained above the suggested cut-off of 90, there was evidence for some change in the clinical significance of the levels of stress reported by individual mothers.

Table 5.7. FIT-DSD intervention group means (SD) at outset and follow-up from the Parenting Stress Index-SF (PSI-SF)

FIT-DSD Intervention Group (n= 13)	Pre-intervention	Follow-up	t-value (df=12)	Significance	Effect Size (Cohen's d)	95 % Confidence Interval
PSI-SF:						
Total Stress	109.84(12.04)	97.00 (13.43)	3.76	.001**	0.97	.16-1.78
Parental Distress	34.69 (5.15)	31.07 (6.60)	2.58	.01*	0.59	19-1.37
P-CDI	32.84 (6.09)	28.38 (4.31)	2.64	.01*	0.81	.02-1.61
Difficult Child	42.30 (6.93)	37.53 (6.91)	3.16	.01*	0.66	12-1.45

P-CDI= parent-child dysfunctional interaction \* Significant at p < 0.05, one-tailed

<sup>\*\* =</sup> Significant at p < 0.01, one-tailed

## 5.5.3.2.2 Family Functioning

Table 5.8 displays the mean score of the FIT-DSD intervention group from outset to follow-up on the general family functioning scale of the Family Assessment Device. At follow-up, the group mean had increased marginally from a mean of 1.74 (SD=.36) at outset to 1.81(SD=.38) at follow-up. There was however no change in the clinical significance of the scores on the general family functioning scale. A paired samples t-test showed that slight variations in scale scores from outset to follow-up were not statistically significant (t(12) = 0.64, p = 0.26, one-tailed). This suggests that the FIT-DSD intervention did not affect family functioning.

**Table 5.8.** FIT-DSD intervention group means (SD) at outset and follow-up from the Family Assessment Device (FAD), Family Habit Assessment Tool (FHAT), Family Crisis Oriented Personal Evaluation Scales (FCOPES) and the Relationship Assessment Scale (RAS)

FIT DSD Intervention Group (n= 13)	Pre-intervention	Follow-up	t-value (df=12)	Significance	Effect Size (Cohen's d)	95 % Confidence Interval
FAD:						
General Family Functioning FHAT:	1.74(.36)	1.81(.38)	.64	.26		
Effective habits	6.29 (.91)	6.23 (.90)	1.32	.10		
Ineffective habits	4.50 (.99)	4.42 (.23)	.71	.24		
FCOPES:						
Total	97.23 (22.42)	103.84 (16.63)	.97	.17		
Reframing	31.30 (7.09)	33.15 (4.20)	1.19	.12		
Acquiring social support	26.46 (8.43)	29.38 (5.95)	.76	.22		
Passive appraisal	15.76 (3.83)	16.00 (2.30)	1.48	.08		
Mobilizing the family	13.76 (3.81)	13.69 (3.09)	.12	.45		
Seeking spiritual support	7.38 (5.57)	9.00 (6.31)	.20	.42		
RAS	22.84 (8.6)	26.23 (2.85)	2.85	.01*	0.51	26-1.29

<sup>\*</sup> Significant at p < 0.05, one-tailed

## *5.5.3.2.3 Family Habits*

Data in table 5.8 from the Family Habit Assessment Tool shows that from outset to follow-up, there was some change in the level of family habits reported in the FIT-DSD intervention group. Effective family habit scores went from a mean of 6.29 (*SD*=.91) at outset to 6.23 (*SD*=.90) at follow-up. Scores on ineffective family habits also saw a similar trend with scores at outset being marginally higher than at follow-up. Two paired-samples t-tests were carried out to assess whether following intervention, the FIT-DSD group reported changes in the nature of family habits. The results of the t-tests failed to reach significance. Taken together with the results presented on family functioning, this suggests that the FIT-DSD intervention had no impact on reshaping the nature of family behavioural habits and family functioning.

## 5.5.3.2.4 Coping Strategies

Table 5.8 also displays means from outset to follow-up for the FIT-DSD intervention group from the Family Crisis Oriented Personal Evaluation Scales, which measure coping strategies. The total score for coping behaviours shows that there was a slight increase at follow-up in the overall number of strategies mothers were using to cope with problems relevant to the family. The group mean was equal to 97.23 (SD=22.42) at outset and had increased to 103.84 (SD=16.63) at follow-up. Additionally, descriptive statistics for subscales comprising the Family Crisis Oriented Personal Evaluation Scales also show that the use of specific types of strategies appeared to have changed at follow-up. For example, the use of reframing situations into a positive light was higher at follow-up. Paired sample t-test were carried out to understand whether the FIT-DSD intervention influenced the way mothers attempted to cope with family problems. The results of the t-tests are shown in table 5.8 and show that changes in mean scale scores for coping failed to reach significance. This suggests that coping strategies did not change over the course of the intervention.

## 5.5.3.2.5 Relationship Satisfaction

The final results presented in table 5.8 display the group means for the FIT-DSD intervention group at outset and follow-up from the Relationship Assessment Scale. The group means suggest that at follow-up, mothers were reporting more satisfaction in romantic relationships. The group mean had increased from 22.84, (SD=8.6) at outset to 26.23 (SD=2.85) at follow-up. Change in standard deviation around the mean implies that mothers were generally scoring higher in relationship satisfaction at follow-up. A paired samples t-test confirmed that mothers reported significantly higher levels of satisfaction in a romantic relationship at follow-up (t(12) = 2.85, p < 0.05, one-tailed, d = .51). The FIT DSD intervention was found to have a moderate effect on relationship satisfaction, suggesting that the intervention acted to facilitate improvements in romantic partnerships for the mothers in this group.

#### 5.5.3.2.6 Personal Stress

Table 5.9 displays the mean depression and anxiety scores for the FIT-DSD intervention group from outset to follow-up. The descriptive statistics show that at follow-up, mothers reported lower levels of depression and anxiety. Depression scores over the course of the intervention had changed from 9.46 (SD=2.50) to 7.92 (SD=2.69) and anxiety scores went from a mean of 10.23 (SD=2.42) at outset to 9.23 (SD=2.71) at follow-up. This suggests some benefit of intervention on personal stress. Paired samples t-test revealed that the FIT-DSD intervention had a moderate effect on reducing levels of depression in mothers of children with ASCs (t(12) = 2.37, p < 0.05, one-tailed, d = .57). Furthermore, table 5.10 shows changes in the clinical significance of the symptoms reported related to depression. Following intervention, mothers who previously scored in the marginally depressed range of the depression scale were now more likely to score in the normal range. One mother however continued to experience clinical levels of depression. Changes in levels of anxiety over the course of the intervention however failed to reach significance.

**Table 5.9.** FIT-DSD intervention group means (SD) at outset and follow-up from The FIT Profiler

FIT DSD Intervention Group	Pre-intervention	Follow-up	t-value (df=12)	Significance	Effect Size (Cohen's d)	95 % Confidence Interval
(n= 13)						
The FIT Profiler:						
Integrity	62.67 (10.98)	65.06 (10.88)	1.52	.07		
Self-responsibility	6.44 (1.54)	6.60 (1.40)	2.90	.01*	.11	66-0.87
Awareness	6.54 (.92)	6.45 (.99)	0.51	.30		
Conscience	8.19 (1.25)	8.36 (1.27)	.67	.25		
Balance	5.09 (1.33)	5.30 (1.04)	.80	.21		
Fearlessness	5.08 (2.36)	5.50 (2.32)	1.73	.05		
Behavioural Flexibility	21.18 (12.98)	23.79 (12.60)	.69	.25		
Depression	9.46 (2.50)	7.92 (2.69)	2.37	.02*	.57	21-1.35
Anxiety	10.23 (2.42)	9.23 (2.71)	.96	.17		

<sup>\*</sup> Significant at p < 0.05, one-tailed

**Table 5.10.** Mothers in the FIT-DSD intervention group scoring in the clinical, marginal and normal range for depression at outset and follow-up

FIT-DSD Intervention	<b>Pre-intervention</b>	Follow-up
Group		
(n=13)		
Depression Range		
Normal	8	11
Marginal	4	1
Clinical	1	1

#### 5.5.3.2.7 FIT Science variables

Descriptive statistics related to how the personal strengths of mothers changed over the course of the FIT-DSD intervention are shown in table 5.9. The data from outset to follow-up shows some change in the personal strengths of mothers. For example, the overall FIT Integrity score increased from a group mean of 62.67(SD=10.98) at outset to 65.06 (SD=10.88) at follow-up. A similar pattern of results was noted for Self-responsibility, Conscience, Balance, Fearlessness and Behavioural Flexibility. Paired samples t-test revealed that the intervention significantly increased levels of Self-responsibility in mothers in the FIT-DSD intervention group (t(12) = 2.90, p = 0.01, one-tailed, d = .11). Cohen's d suggested a small effect of intervention on improving personal strengths of mothers in this area. The results from outset to follow-up for the strength of Fearlessness were close to significant, tentatively suggesting that the FIT-DSD intervention enhanced Fearlessness in mothers of children with ASCs (t(12) = 1.73, t = 0.05, one-tailed).

# 5.5.3.2.8 Discussion of data analysis from outset to follow-up for the FIT DSD intervention group

The results in section 5.5.3.2 exploring changes in the FIT-DSD intervention group on important study dependent variables suggest that the intervention had a moderate to large effect on helping mothers manage their level of parental stress. For total parenting stress, a large effect of intervention was observed (d=.97) and moderate to large effect of the intervention in the three areas of parental stress comprising the total stress score were also noted (Cohen's d between .59 and .81). The intervention also had a positive effect on personal stress, specifically on levels of depression, which were lower following intervention. The effect of the intervention on levels of depression was moderate in reference to the reported Cohen's d of .57. Furthermore, the intervention had a moderate effect on improving scores in satisfaction in a romantic relationship (d= .51). Finally, there was evidence to suggest that the FIT-DSD intervention enhanced the personal strengths of mothers, specifically in Self-responsibility (d = 0.11). There was also some evidence

to suggest that intervention improved strengths in Fearlessness, although the results did not reach statistical significance.

The FIT-DSD intervention did not appear to significantly influence perceptions of general family functioning, the types of habits within the family environment or the types of coping strategies mothers used to resolve issues relevant to the family. Overall the results suggest that the FIT-DSD intervention was successful in helping this group of mothers address some of the problems they are reported to experience. Broadening the behavioural repertoire of mothers also brought about benefits in their profiles of personal strengths.

# 5.5.4 Did the number of Do Something Different tasks attempted affect the experience of total parental stress?

Over the course of the intervention, mothers were asked to use two types of cards-expander and disrupter. Both of the cards were designed to broaden the behavioural repertoire of mothers and therefore the distinction between the two types of resources used is not relevant to the study outcomes. This is because both resources were deemed equally suitable to expand a mother's behavioural repertoire and work on developing personal strengths. It is however important to understand whether the overall number of tasks attempted within the intervention period influenced the benefits mothers reported in parental stress- the area where the intervention had the most prominent effect. This might provide insight into whether this type of intervention can only be effective if 'concentrated' intervention occurs (i.e. a high number of tasks attempted).

To address the above, difference scores were calculated for mothers in total parenting stress from the Parenting Stress Index-Short Form. This was achieved by subtracting the outset score from the follow-up score in total parenting stress. Negative difference scores denote improvement in parenting stress. The difference scores for each mother within the FIT-DSD intervention group (n=13) are presented

in table 5.11. Table 5.11 also shows the number of DSDs the mothers attempted over the intervention period.

The data in table 5.11 shows that with exception to one mother, most mothers completed between 24 and 60 DSD tasks over the course of the intervention period. Table 5.11 also suggests that there is not a consistent trend between the number of DSDs attempted and improvements in total parental stress i.e. the mother who attempted the most DSDs did not report most improvement in parental stress. A Pearson's correlation between improvements in total parental stress and the number of DSDs attempted was carried out to understand more about the association between the extent of engagement with the intervention and benefits to parental stress. The correlation revealed no association between the number of DSD tasks attempted and the extent of improvement seen in total parental stress (r(11) = -.23, p = .44, two-tailed).

It was anticipated that as the DSD intervention works on improving the personal strengths of mothers, it is not the number of tasks attempted that is associated with benefits gained. The nature of change in personal strengths might be responsible for observed improvements in levels of parenting stress. Self-responsibility was the only strength that was significantly enhanced by the FIT-DSD intervention. A difference score for Self-responsibility was therefore calculated and correlated with the difference score in total parenting stress. The difference score for Selfresponsibility was calculated by subtracting the follow-up score from the outset score and so positive scores indicate the extent of improvement seen in this area. A negative association was anticipated between difference scores in Selfresponsibility and total parenting stress. This is because greater increases in Selfresponsibility over the course of the intervention should be associated with lower levels of parenting stress. The Pearson's correlation revealed a significant negative association between the two sets of difference scores (r(11) = -.53, p = 0.03, one tailed). This suggests that by changing a mother's profile of personal strengths, the FIT-DSD intervention helps mothers cope better with raising a child with an ASC.

**Table 5.11.** Difference scores showing improvement in total parental stress and Self-responsibility for mothers in the FIT-DSD intervention

FIT-DSD Intervention Group (n=13)	Difference score from outset to follow-up in total parenting stress	Total number of DSD tasks attempted	Difference score from outset to follow-up in Self-responsibility
Parent			
1	-19	27	1.00
2	-1	10	30
3	-9	29	1.00
4	-19	31	.70
5	-9	24	.30
6	-5	43	.60
7	+5	60	1
8	+1	29	0
9	-14	60	40
10	-13	44	.60
11	-24	29	-1.00
12	-18	37	1.20
13	-42	59	1.30
Overall mean	- 12.84 (12.31)	37.07 (15.41)	.46 (.57)

Negative difference scores in total parenting stress indicate mothers who reported feeling less stress in being a parent at follow-up. Positive difference scores in Self-responsibility indicate mothers who have developed more Self-responsibility at follow-up. (SD).

#### 5.6. Discussion

This study reported findings from the first RCT of an intervention designed to improve personal strengths in mothers of children with ASCs. The intervention was designed to help mothers tackle problems in personal and family well being that are well documented in the literature on ASCs and family life. Past research in this area has relied on parent training to tackle problem behaviours in the child and to develop parent understanding of and skills in managing ASCs. Parent training, although effective, carries a number of limitations in relation to managing stress in this group of parents. These limitations relate primarily to the cost and availability of parent training interventions and also the effectiveness of intervention in relation to parental time invested.

In light of the association that was demonstrated between characteristics of parents (i.e. study three of this thesis) and stress when raising a child with an ASC, this study explored the usefulness of the FIT-DSD intervention for enhancing personal strengths and tackling parent and family stress in mothers of children with ASCs. Previous applications of the FIT-DSD intervention have shown it to be effective for managing stress in a range of different areas. This study evaluated the usefulness of the FIT-DSD intervention for helping mothers of children with developmental conditions such as ASCs.

**Table 5.12.** Effectiveness of interventions employing parent training with parents of children with Autistic Spectrum Conditions

Study	Aims	Type of Intervention	Parent Measures	Sample Size	Effect Size	Effect Size for local service intervention or 'no treatment control'
Drew et al (2002)	Improving joint attention and joint attention routines in young children with autism	Parent training	Parenting Stress Index (total stress)	N=10	.43	LS =.08*
Chadwick et al (2001)	Reducing problem behaviours in children with severe learning difficulties (16% of children were autistic)	Parent training	Parenting Stress Index- Short Form (parental distress)	N= 23	.44	NTC= =.01*
Remington et al (2007)	Evaluating the outcomes of early intensive behavioural therapy in children with autism	Parent training	Hospital Anxiety and Depression Scales	N= 23	Anxiety=.24 Depression=.02	LS Anxiety= .25 LS Depression=.37
Sofronoff & Fabrotko (2002)	Reducing problem behaviours in children with Asperger syndrome	Parent training	Parent Self- efficacy	N= 18	.77	NTC=.26*

LS= effect size for comparison group receiving local service intervention, NTC= effect size for no treatment control. \*= Negative effective size (scores at follow-up were worse than baseline).

# 5.6.1 Summary of main findings

# 5.6.1.1 Parenting Stress

Overall, the FIT-DSD intervention was effective in reducing parenting stress, depression and in improving satisfaction in a romantic relationship for mothers of children with ASCs. Total parenting stress in mothers receiving the intervention fell from a group mean of 109.84 to 97.00 over the course of the study. The intervention had a large effect on total parenting stress (d= 0.97). On average, mothers in the intervention group saw a reduction of 13 points in total parenting stress at follow-up. Scores in total parenting stress at follow-up ranged from 74 to 120 whereas at outset scores in the intervention group ranged from 84 to 131. There was also a change in the clinical significance of total parenting stress scores, with more mothers scoring in the normal range at follow-up. Taken together these results suggest that the FIT-DSD intervention helped mothers manage their level of total parenting stress.

The intervention was also seen to have a moderate to large effect on individual areas of parenting stress that contribute to the total parenting stress score. The most noticeable improvement was related to parent-child dysfunctional interactions (d=.81). This suggests that the intervention helped mothers re-evaluate their perception of their child, including whether the child has a negative impact on the parents life and whether the child has lived up to the parent's expectations (Abidin, 1990). Additionally, the FIT-DSD intervention had a moderate effect on helping mothers manage difficult child behaviours and feelings of parental distress (the extent of stress experienced due to personal factors such as restrictions placed on other life roles).

It is important to note the mothers in the FIT-DSD intervention group did not differ to mothers in the wait list control group on entering the study in terms of the level of parenting stress they experienced and their family background (including the extent to which their children had been affected by an ASC). At follow-up, no change was seen in the control group in relation to parenting stress. This suggests that

parenting stress in mothers of children with ASCs, without intervention, remains consistent over time and is relatively high. This is inline with the findings of other research studies documenting high levels of parenting stress in parents of young and older children with ASCs (e.g. Davis & Carter, 2008).

Furthermore, mothers who took part in this study and particularly the FIT-DSD intervention group did not represent a unique group in the sense that they were experiencing less problematic levels of parenting stress than previously documented in this group. For example, Tomanik, Harris & Hawkins (2004) measured parenting stress using the Parenting Stress Index- Short Form in 60 mothers (M=37.75) of children with autism (M=5.05) and reported an average level of total parenting stress of 97.35 (SD=20.16) (range of scores between 53 to139). This data is comparable with the level of stress reported in the sample of mothers who took part in this study. In fact, the average level of parenting stress at outset in mothers in the FIT-DSD intervention group was higher than that reported in Tomanik et al's (2004) study (M=109.84, SD=12.04). This suggests that the FIT-DSD intervention may in fact be useful for mothers experiencing very high levels of parenting stress.

The FIT-DSD intervention also had a large effect on total parenting stress, with minimal support from a professional. This is particularly important in light of the findings of studies employing parent training. Parent training typically involves contact over a specific period of time (e.g. 6 weeks) with a professional who trains parents in how to manage child behaviours. Parent training is therefore related to investment in time for parents and a high cost for service providers. Table 5.12 shows the results of parent training interventions that have previously been employed and measured the effect of intervention on parent variables such as parenting stress, depression, anxiety and self-efficacy. The data presented, with exception to the study by Chadwick, Momcilovic, Rossiter, Stumbles & Taylor (2001), relates only to mothers of children with ASCs. The data available in these studies allowed for the calculation of effect sizes for the individual interventions.

Firstly, an important point to note from table 5.12 is that where the outcome of intervention for parenting stress was measured, the effect sizes were smaller than those reported for the FIT-DSD intervention. The Cohen's d for the FIT-DSD intervention for total parenting stress was equal to .97, where as the effect size in the parent training intervention in the study reported by Drew et al (2002) was .43. Similarly, Chadwick et al (2001) developed a parent training intervention delivered either over group or individual sessions for parents of children with severe learning difficulties (of which 16% were raising children with ASCs). Data relating to the parental distress subscale of the Parenting Stress Index-Short Form showed a moderate effect of intervention to help tackle parental distress in those receiving the intervention as individual sessions. Where studies employed local service control groups or control groups receiving no known intervention, the data suggest either no change overtime in parenting stress (as reported in this study), or scores in parenting stress becoming marginally more problematic overtime. Although the data presented in table 5.12 is not an extensive summary of studies employing parent training, the summary does show that the FIT-DSD intervention fairs well against other interventions developed for parents of children with ASCs and severe learning difficulties.

## 5.6.1.2 Relationship Satisfaction

Research early on into ASCs and family life has shown that parents experience many problems in marital relationships, which have often been attributed to the stress of raising a child with an ASC (e.g. see Bristol, 1987). This is important because stress in the marital relationship can bring about broader consequences for family well being, including problems in sibling adjustment to ASCs and psychological functioning (Rodrigue, Geffken & Morgan, 1993; Rivers & Stoneman, 2003). A review of the literature found that recent research specific to ASCs has however failed to assess how interventions benefit the relationship between parents. For example, none of the studies cited in table 5.12 looked at the impact of intervention on the marital or couple relationship. Using the Relationship Assessment Scale, this study however found that intervention aimed at improving the personal strengths of

mothers can indeed have a positive effect on indicators of the health of the relationship between parents, as noted in an increase in relationship satisfaction. At outset, the mean relationship satisfaction score of mothers in the FIT-DSD intervention group was 22.84 (SD=8.6). This score was 26.23 (SD=2.85) at follow-up. Importantly, variation around the group mean also fell at follow-up, indicating that the results are not simply due to the data of one or two mothers skewing the results. At the same time, relationship satisfaction within the control group did not change across the study; once again suggesting that without intervention, many of the problems faced by mothers of children with ASCs are likely to remain consistent.

The FIT-DSD had a moderate effect on improving maternal satisfaction in a romantic relationship (d=0.51). This is comparable to past research. For example, Barlow, Coren & Stewart-Brown (2002) carried out a meta-analysis of studies employing interventions to improve maternal psychological well being. Of the seventeen studies included in the meta-analysis, only four measured the effect of intervention on the relationship of parents. Although this review was not specific to mothers of children with disabilities, it found that studies reported effect sizes in favour of intervention (d = -0.4, 95% confidence interval = -0.7 - -0.2). The FIT-DSD intervention, at least in the short-term, had a marginally larger effect on improving satisfaction in a romantic relationship, with a reported effect size of 0.51 (95%) confidence interval = -0.26-1.29). This provides promising results for the FIT-DSD intervention as a means to help mothers of children with ASCs tackle broader family problems, where more time intensive training with parents of children with intellectual disabilities has found no effect of intervention on the quality of the relationship between parents. For example, McGaw, Ball & Clark (2002) found no effect of a group based intervention delivered over fourteen weeks (total of 28 hours of intervention) on the quality of relationship between parents of children with intellectual disabilities.

#### 5.6.1.3 Personal Stress

There is much research documenting the negative impact of raising a child with an ASC on maternal levels of psychological distress, including depression and anxiety. For example, recent research by Olson & Hwang (2008) showed that 50% of mothers of children with autism report clinical levels of depression. This compares to 15 to 21% of mothers reporting elevated levels of depression with either typically developing children or children with other forms of intellectual disabilities. The lifetime prevalence of depression in women in the general population has further been reported to lie between 7 and 21% (Clarke & Beck, 1999). This clearly demonstrates that mothers of children with ASCs are at increased risk of experiencing psychological distress.

The results of this study and those of others have shown that psychological distress in mothers of children with ASCs is responsive to intervention. For example, a study by Bristol, Gallagher & Holt, (1993) used a psychoeducational intervention with the aim of improving the ability of parents to modify behaviours of their children by reinforcing positive or desirable behaviours. Compared to a control group, Bristol et al (1993) found that mothers receiving intervention saw significant improvements in their level of depression at 18-month follow-up. This is important because at 6month follow-up, there was no evidence for the intervention having helped mothers tackle levels of depression. Over 18 months, the mean level of depression reported by mothers in the intervention group in Bristol et al's (1993) study went from 15 (SD=10.50, N=14) at outset, to a mean of 9.71 (SD=7.11) at follow-up. The effect size of the intervention was therefore equal to .57. The control group on the other hand showed an increase in levels of depression from a group mean of 12.57 (SD=9.32, N=14) at outset and a mean of 16.71 (SD= 10.19) at 18 month follow-up. Depression was measured using the Community Epidemiological Depression Scale (Radloff, 1977).

Results from mothers who took part in the FIT-DSD intervention were comparable to those reported by Bristol et al (1993). The FIT-DSD intervention was successful in reducing levels of depression, as measured by the Thoughts and Feelings Scale of The FIT Profiler. Prior to taking part in the intervention, mothers in the intervention group had a mean depression score of 9.46 (SD=2.50). This fell to a mean of 7.92 (SD=2.69) at follow-up. The effect size of the intervention on levels of depression was .57. This suggests that the FIT-DSD intervention is as effective at reducing levels of depression as parent training programmes focusing on skills training. Additionally, the study found that without intervention, levels of depression in mothers of children with ASCs are unlikely to significantly change over time.

The FIT-DSD intervention did not have a significant effect on maternal levels of anxiety, nor did levels of anxiety change in the wait list control group. This is comparable to the results of other studies suggesting that anxiety is more difficult to tackle in this group than levels of depression. A study by Sharpley et al (1997) for example asked both mothers and fathers of children with ASCs to complete the Self-Rating Anxiety Scale (Zung, 1971). The study found that nearly 42% of parents reported moderate levels of anxiety, compared to only 13.2% of parents reporting moderate levels of depression. This suggests that anxiety is a prominent issue for parents of children with ASCs and an area where more research is needed in light of these symptoms being less 'treatable' with parent training and interventions targeting the personal strengths of parents.

#### 5.6.1.4 FIT Science variables

Although past research has shown that the characteristics of parents such as hardiness, coping styles and self-efficacy are associated with well being (e.g. Weiss, 2002), no research has specifically attempted to target the characteristics of parents that facilitate adjustment ASCs. The research that has looked at improving coping in parents has tended to assume that the child has a deterministic effect on coping and therefore by dealing with difficult child behaviours, parent well being can be

improved. This may, in some cases be true. However, not all parents experience depression, anxiety and other problematic outcomes when raising a child with an ASC. This suggests that characteristic of the child do not have a deterministic effect on parents. This study found no association between the extent of autistic characteristics reported by mothers for their child and the level of total parenting stress (r(22) = .17, p = 0.41, two-tailed, N = 24) reported by the sample of mothers who took part in this study. This suggests that characteristics of parents should also be an important focus for intervention studies.

This study showed that by targeting personal strengths in areas of FIT Science, mothers can be helped in significantly improving their ability to manage both parental stress and depression and also improve their satisfaction in a romantic relationship. These are all areas documented in the relevant literature as being problematic for mothers of children with ASCs. The study showed that with no intervention, the personal strengths of mothers are unlikely to change in the shortterm and where change does occur, this may not be beneficial. In this study for example, the wait list control group saw a decrease in the personal strength of Balance from outset to follow-up. This could be explained in terms of the changes mothers may have to contend with in the child's life cycle that means at times, caring for a child absorbs more or less of the parent's time and energy. There is however limited, if any research, looking at how mothers balance their day-to-day life, although it is clear that caring for a child with ASC is highly demanding (Kogel et al, 1992; Sanders and Morgan, 1997). Anecdotal evidence does however suggest that issues such as change of schools and other important transitions take up more parental time.

Although both groups of mothers in this study had comparable profiles of strengths at outset, the FIT-DSD intervention group at follow-up showed significant improvements in Self-responsibility. The group mean for Self-responsibility went from 6.44 (SD=1.54) at outset to 6.60 (SD=1.40) at follow-up. The intervention had a small effect on increasing Self-responsibility in mothers (d=.11), with some evidence

to suggest that intervention was beginning to improve Fearlessness also. Moreover, the study showed that in the intervention group, improvements in total parenting stress were significantly associated with increasing strengths in Self-responsibility and not the extent to which mothers engaged with the FIT-DSD tasks. This demonstrates the powerful effect of the characteristics of mothers on personal outcomes in the context of ASCs. The findings suggest that when mothers begin to take responsibility for their actions and the way 'their world' is, they can empower themselves to also shape the impact of their child on personal outcomes. In addition to skills training, interventions targeting the personal strengths of mothers should be promoted in this group. The results of this study suggest that intervention targeting strengths in areas of FIT Science are as, if not more effective, than other time and resource intensive programmes that have been implemented with this group in particular.

## **5.6.2 Strengths and Limitations**

#### 5.6.2.1 *Outcomes*

The FIT-DSD intervention did not significantly improve levels of anxiety. Additionally, the results related to family functioning, family habits and coping strategies also failed to reach significance, suggesting that the intervention did not help mothers tackle broader family issues or to reshape their natural styles of coping with family problems. The results relating to family functioning were particularly surprising in light of the consistent relationship between FIT variables and perceptions of family life reported throughout this thesis.

With reference to family functioning, the control group reported significantly more problems than the FIT-DSD intervention group at outset, and these problems persisted at follow-up. There was also a marginal change in the FIT-DSD intervention group to show problems in family functioning increasing over time from a group mean of 1.74 (SD=0.36) at outset to 1.81 (SD=0.38) at follow-up on the general family functioning scale. At the same time, in the intervention group, satisfaction in a romantic relationship significantly improved. It is therefore unclear

why the intervention did not have a significant effect on strengthening family functioning. It may be that in reference to satisfaction in a romantic relationship, mothers, as a result of taking part in the intervention, had re-evaluated their relationships and come to realize that things were in fact better than they had assumed. This re-evaluation could, for example, have been related to tackling levels of depression. Improving family functioning on the other hand might require not only the mothers to re-evaluate the situation and their behaviour, but other members of the family to also adapt and together bring about a change. This, as shown in this study, might be difficult to achieve in the short-term by targeting the personal strengths of mothers; although it is clear from this thesis that personal strengths are closely related to the way mothers perceive their family functioning. In the short-term, attempts made by mothers at trying to change family dynamics might also have resulted in resistance from others and contributed to things perhaps getting worse before improving. To understand if this is a valid explanation of the results, a longer follow-up of mothers would have been necessary and this is an area where future research could prove useful in understanding the extent to which the FIT-DSD intervention produces sustainable results.

## 5.6.2.2 Statistical Analyses

Data from outset to follow-up between groups was analysed in this study using repeated measures t-tests over a 2 factor repeated measures ANOVA design. This is because the results of an ANOVA would have accounted for variation between groups at outset and therefore inflated the likely effect of time over the effect of group. This may have led to Type 1 errors resulting in rejecting the effect of the FIT-DSD intervention, over a general effect of time. For example, a 2 factor ANOVA was carried out entering depression as the dependent variable, and each group (FIT-DSD intervention and control) and time (outset and follow-up) as fixed factors. The results of the ANOVA showed there to be a significant main effect of time (F(1,22) = 4.79, p < 0.05), with no main effect of group (F(1,22) = 3.86, p = 0.06). The interaction between time and group also failed to reach significance (F(1,22) = 2.98, p = .98). Two repeated measures t-tests however confirmed that over the course of

the study, there was no change in the level of depression reported in the control group, whereas the FIT-DSD intervention group reported significantly lower levels of depression at follow-up. After running both types of analyses on the data, it was thought appropriate to report the results of the repeated measures t-tests, which most accurately captured the changes brought about by the intervention.

## 5.6.2.3 Sample

The FIT-DSD intervention group was comprised of thirteen mothers, and a further eleven mothers were in the wait list control group. This is a relatively small sample size for an intervention study. Nonetheless, mothers of children with ASCs have high demands on their time and are a difficult group to recruit. Therefore, the study limitations are overcome by a low attrition rate, with 100% completion in the FIT-DSD intervention group and 85% completion rate in the wait list control group. Furthermore, the study recruited a fairly homogenous group of mothers as all were White British and relatively well educated. The extent to which the FIT-DSD intervention might help mother from different social economic class groups and different cultural backgrounds is therefore unclear.

## 5.6.2.4 Strengths of the study

A major strength of this study is the 100% completion rate for mothers in the FIT-DSD intervention group. For any intervention to be effective, participants must be motivated to engage with the intervention. The lack of attrition in this group suggests that mothers were motivated to use the FIT-DSD intervention and the intervention might therefore be well suited to this group. Furthermore, the FIT-DSD intervention, with minimal training in the intervention techniques, was successful in bringing about significant improvements for mothers in the areas of parental stress, psychological health and in relationship satisfaction, which are prominent areas of difficulty for this population. The benefits of the FIT-DSD intervention in these areas were also comparable to other types of interventions reported elsewhere in the literature on ASCs and family life. The study was also unique in its attempt at specifically targeting the personal strengths of mothers, whereas past research has

relied heavily on reducing problem behaviours in the child, perhaps overemphasizing the deterministic effect of children with ASCs on parental well being.

Additionally, the impact of intervention was also measured on a constellation of indicators of maternal 'coping', whereas past research has tended to look at variables in isolation. Finally, this was a carefully designed RCT study, in which mothers were unaware of whether they were receiving a true intervention or a placebo. It is therefore unlikely that the benefits observed are due to individual differences or the confounding influence of mothers believing the intervention will help them.

#### 5.6.3 Conclusions

This study has highlighted the importance of considering the role of personal strengths in promoting resilience in mothers of children with ASCs. Past research in this area has relied on parent training programmes, which have overestimated the association between child behaviours and the stress experienced by parents. These studies have assumed that helping parents understand and re-shape child behaviour will have positive effects on the family. Whilst this is true, other studies have also shown that some parents cope better with raising children with ASCs because of their own resources for coping. This is consistent with the finings of study three of this thesis. This study, using an RCT of the FIT-DSD intervention, has further shown that interventions aimed at developing the personal strengths of mothers of children with ASCs can have comparable, if not better results, in helping them tackle some of the problems they experience. Furthermore, as the first demonstration of this sort, the study has many implications for service providers in relation to offering more time and cost effective interventions to support this group. The intervention reported has the added benefit of being widely applicable to mothers in different stages of their child's life cycle and has a low attrition rate.

To further evaluate the utility of the FIT-DSD intervention for helping mothers, the following chapter turns to reporting a qualitative analysis of the thoughts of

mothers who took part in the FIT-DSD intervention group. The analysis focuses on highlighting the impact of ASCs on family life, the need for intervention and why, if at all, mothers believed they benefited from the FIT-DSD intervention.

## Chapter 6

Study five: A qualitative investigation of the experience of mothers with the FIT-DSD intervention

#### 6.1. Introduction

The purpose of this study is to provide an in-depth understanding of the experience of mothers who took part in the FIT-DSD intervention. Questionnaires were completed at outset and follow-up in the RCT of the FIT-DSD intervention. This provided extensive quantitative data that helped explore the impact of the FIT-DSD intervention on a number of indicators of maternal and family well being. The results showed that without the intervention, mothers of children with ASCs report their life and family 'stressors' as relatively stable or unchanging over the short term. In contrast, mothers in the FIT-DSD intervention group managed their parental stress and depression better and were able to re-evaluate their perspective on their romantic relationship. The FIT-DSD intervention was designed to break habitual behaviours of mothers in stressful situations and to expand their behavioural repertoire. It was predicted this would be reflected in enhanced Self-responsibility, among other things.

On completion of the RCT study, mothers in the FIT-DSD intervention group were also interviewed about their experience of raising a child with an ASC and to explore their views on the intervention itself. The interviews aimed at providing an in-depth account to support the research literature as to why mothers experience such high levels of stress. More importantly, the interviews allowed exploration of whether mothers believed intervention benefited them and how, if at all, the FIT-DSD intervention could be developed further. Qualitative investigation enriched the data by capturing broader benefits mothers experienced that were not measured by the questionnaires.

Maternal experiences were explored using grounded theory. Grounded theory allows for the development of a substantive theory, where the processes of data collection, analysis and theory generation are closely linked together. This provides a rich account of people's thoughts, feelings and actions in the context of the topic of investigation (Charmaz, 2006; Strauss & Corbin, 1998). Grounded theory was selected for this study because it offers a flexible methodology where a researcher can start with an understanding of the area of study and work on elaborating themes or purely explore themes emerging from the data (Strauss & Corbin, 1998).

There is much research on how mothers and the broader family are affected by raising a child with an ASC and this research has been explored in detail in chapters four and five. Exploration of the literature helped elucidate themes that were distinct within the many studies in this area, and also those that had not been explicitly investigated. For example, although much of the literature has focused on the negative impact of ASCs on family life, few studies have explored parent views on more positive characteristics of having a family, which includes a member affected by an ASCs. Anecdotal evidence suggests that many parents see desirable attributes in their children, and this is a largely neglected area. Secondly, research into ASCs and family life has lacked qualitative investigation into day-to-day experiences of families and has tended to subsume hassles under themes such as 'marital discord', and 'isolation' without full consideration of the processes contributing to the unique profile of stress. This study aimed to provide greater insight into how ASCs affect families by providing a richer description of daily stresses. Additionally, using exemplary analytic methods from grounded theory, the study aimed to expose the conceptual links between themes and look at why, in the view of mothers, the FIT-DSD intervention was useful in tackling some of the stresses they experience.

#### 6.2. Method

# 6.2.1 Participants

Mothers who took part in the FIT-DSD intervention study (n=13) were interviewed following completion of the RCT. The mothers had a mean age of 40 (*SD*=7.59). Ten mothers were married, 2 mothers were separated or divorced and one was a single parent. All were White British and just over 60% were educated to graduate or postgraduate level. Seven of the mothers were also employed. Six mothers had children with 'severe' diagnoses of autism and six had children with 'mild-moderate' autism according to data collected from the Childhood Autism Rating Scale in study four. Interviews were carried out within the mother's own homes within three weeks of completion of the RCT.

#### **6.2.2** The Interview Schedule

Based on themes emerging from existing research into ASCs and family life, a semistructured interview schedule was developed. The interview schedule broadly covered first impressions of the child's behaviour, diagnosis, day-to-day family life and marital relationships. The questions in the interview schedule were non suggestive so that the experiences of mothers reflected reality, and not preconceived ideas from the research literature on the negative impact of ASCs on families. Mothers were also asked about characteristics of ASCs that were desirable and about their expectations and experiences of the FIT-DSD intervention. Examples of questions included in the interview schedule are: 'What's good about having a child with autism?'; 'When did you first become aware that your child might have autism?'; 'How do you think caring for a child with autism has affected your day-today life?'; 'What behaviours have you developed as a family to help you cope with day-to-day life and any specific challenges associated with autism?'; 'How easy or difficult did you find it to engage with the FIT-DSD intervention?'; 'Have you noticed any benefits of having taken part in the intervention?'; 'Do you have any suggestions for how the intervention could be developed?'

### 6.2.3 Procedure

Mothers were interviewed individually and interviews were recorded and transcribed using grounded theory processes, as described by Charmaz (2006). The main features of grounded theory include theoretical sampling, data coding, the constant comparative method, the generation of categories, memo writing and finally, theory generation, all of which occur simultaneously to ensure the emerging theory is grounded within the data (Strauss & Corbin, 1998). Data from the first four parent interviews was transcribed and coded by the lead researcher. Transcriptions of the interviews were then given to a further three researchers who went through each transcript and identified meaningful fragments of the transcriptions and assigned to these descriptive codes. The four researchers then explored their individual coding frames to reach consensus about the descriptive codes assigned to the transcriptions. The lead researcher then used the constant comparative method to make analytic distinctions between the descriptive codes and to generate conceptual categories. The conceptual categories help develop an analytic framework, giving the categories definition in a narrative manner. Categories capture processes within the data and subsume themes and descriptive codes emerging. The lead researcher then produced memos, which elaborate on the ideas, themes and codes captured within conceptual categories and give direction to future coding. At this stage, raw data from the interviews was brought into the memos to validate the processes captured and provide support for the analytic claims made. The lead researcher then proceeded with further theoretical sampling and carried out an additional six interviews after which the above process was repeated to ensure the emerging theory was an accurate reflection of the data. The final three interviews were then carried out and the lead researcher simultaneously worked on refining and testing the emerging theory.

## 6.3 Analysis and Results

Several themes emerged from the data, each of which will be discussed in turn below:

- 1. Early experiences and diagnosis
- 2. The nature of ASCs
- 3. Maternal and family stress
- 4. Resources for coping
- 5. The FIT-DSD intervention

# 6.3.1 Early experiences and diagnosis

Mothers described becoming aware their child was not developing as they would expect from 0 to 36 months of age. Seven of the mothers had observed how their child was either very different from siblings at the same age or peers. Two mothers had elder children already diagnosed with an ASC and therefore recognized it was highly likely that their younger child was also on the autistic spectrum. One mother also commented on how she first suspected her child was displaying atypical behaviour by observing striking similarities between her own child and another who she knew was autistic 'I'd just started taking her to an opportunity class and there was another little boy who was almost exactly the same and he had just been diagnosed. They weren't very different, almost striking characteristics that were the same. They weren't identical in any way shape or form but a lot of traits that he showed I spotted in her and as a result of that I did quite a lot of research (Parent 13). A further parent had not realized her child was displaying atypical development until a nursery teacher pointed this out. Until then, the mother had just assumed she had a child who liked being alone 'He'd been in a private nursery that my other two children went to and he was there for almost a year and was about to leave to go to a state nursery and the teacher, she said to me that we have some concerns about H's development. I think deep down I knew he was slightly different but I just thought that I had an easy child because he would go off and play in the garden on his own and wasn't particularly um, difficult to sort of mould. I just thought that this is the way the child is, by himself. But anyway, she sat me down and went through all the issues that

their child was different from the moment they gave birth 'I honestly thought that the day after she was born. People don't believe me when I say that but it was really I felt she was not like other babies and literally from the moment she popped out. And um, I remember the day after she was born. Her startle response was much sharper, she could hear other babies across the room and just kept startling and that's something she continues to do and is just very uncomfortable in her own skin' (Parent 1).

When mothers finally accepted their need to discuss their child's behaviour with a professional, all reported speaking first to either their GP or health visitor. Two mothers who first discussed the issue with their health visitor were very disappointed with the response received. One of the mothers was told 'you should just stop worrying and be happy you have a happy and healthy child' (Parent 5) and the other was told 'no, no, no, there there dear, he's just a bit, you know boys, a wee bit slower don't worry about it' (Parent 6). These mothers reported feeling frustrated that their concerns had been dismissed and consequently doubted their intuition.

Three mothers received diagnoses through private health care and reported the service to be as smooth as it could be but were aware of how difficult this could have been had they have gone down the usual route. Ten mothers therefore relied on GP referrals, which saw mixed responses. Often mothers felt they had more knowledge and were 'telling' their GP their child is autistic, where the GP apparently lacked knowledge on, and or confidence in making a referral. In the main, the problem however began on referral with having the process of obtaining a diagnosis started. Mothers often felt trapped within the system and had to wait at least between 3 to 6 months if not longer for a diagnosis to be given. In the processes, they were often having to move between seeing different professionals and felt a multi-disciplinary team, including all those involved in their child's healthcare within a single centre would have been much more effective.

Children in this study received a diagnosis between 24 months to 5 years, with the majority of mothers viewing the process as time consuming, frustrating and confusing. 'Our GP was generally very good and made a referral for us and it was all down hill from then. We waited months for an appointment to come through and thought that's it, we'll finally be able to get a label for his difficulties and begin to understand more but the paediatrician was most unhelpful. Nothing happened except more visits bouncing between speech and language therapists, the health visitor, all of which was very draining. My husband had of course lost interest by then and left me to deal with the appointments... I was angry but I didn't know who to grab and shout and say, my child is autistic. We finally saw a different paediatrician who realized T has serious difficulties and a label was given. I felt so upset. Sounds funny since I just said I knew he was autistic. But now it was real if you can see what I mean? It's like grieving for something all over again. It took me a few months to come to terms with it and I just thought, right, I have to do it for him' (Parent 8). 'Testing and everything was done and we saw it all written in black and white, that was the hardest, when you actually see it written down because that's what the reports are. You see it written what they can't do when you think but he can do this and he can do that...its really upsetting. That bit was the hardest and actually seeing it in black and white was just horrid although I knew' (Parent 6).

Mothers in this study reported comparable experiences to those documented in the literature on ASCs. Studies have shown traits of ASCs can be reliably identified in children within 18 months (Howlin & Asgharian, 1999; Osterling & Dawson, 1994). Although much is known about problems associated with the diagnosis of ASCs, there are few studies documenting the processes parents engage in to help them accept their child is displaying atypical development. The data gathered from mothers in this study suggests that four processes are important in identifying autistic traits:

- 1. Comparing the child to elder, typically developing siblings at the same age.
- 2. Comparing the child to typically developing peers.
- 3. Comparing the child to other children with disabilities.
- 4. Guidance from professionals such as teachers.

It is important to highlight these processes as knowledge amongst professionals could help facilitate acceptance and recognition of symptoms from parents. For example, teachers, when making parents aware of how their child's behaviour is different from typically developing children might benefit from talking to parents about what most children are able to do at the child's age. This might facilitate parents to engage in making comparisons between their child and peers and allow them to explore the extent of difference between the two. Most research on early experiences of ASCs has however focused on the 'symptoms' parents notice and their emotional reactions to these including anger, guilt, frustration and resentment (Gray, 1994).

Maternal accounts of the process of diagnosis also reflect findings in the literature. Within the UK, the National Autistic Society (2010) states that the diagnosis procedure usually begins by GPs making referrals to professionals such as psychiatrists, paediatricians and clinical psychologists, all of whom can help in the process of initial diagnosis. Where parents are seen to bounce between services such as a psychiatrists and speech and language therapist, this reflects the multidisciplinary approach to diagnosis (National Autistic Society, 2010). The process of diagnosis is a common theme within the literature, with many researchers highlighting diagnosis as being very challenging for parents emotionally (Howlin & Asgarian, 1999; Siklos & Kerns, 2007). In a large scale study, Howlin & Asgarian (1999) further found that the average age of diagnosis for children with autism in the UK was 5.5 years. This suggests the experiences of diagnosis of mothers in this study are unlikely to differ vastly from other families as all children received a diagnosis between the ages of 24 months to 5 years. Finally, it is also important to mention that some mothers reported receiving a diagnosis as similar to a grieving

process or one related to shock, even though they had accepted their child displayed developmental difficulties. This is not uncommon. Post-diagnosis has often been likened to a state of grieving where parents are struggling to come to terms with their child's limitations, especially given the child's disability is 'invisible' (Mansell & Morris, 2004; Sullivan, 1997). The results of this study support the general themes in the literature and offer professionals avenues to explore in supporting parents to recognize early signs of ASCs and to work on reducing the emotional turmoil parents report during the process of diagnosis. This might include multi-disciplinary appointments so that parents obtain a diagnosis within a shorter time frame and services to support parents in the emotional turmoil experienced pre, during and post diagnosis.

## 6.3.2 The nature of Autistic Spectrum Conditions

Mothers were able to discuss several features of ASCs that first made them express concerns over their child's behaviour to professionals and many, which continue to differentiate their child from others. The most commonly expressed traits of ASCs were language delays, problems in relating to others, preference for time alone, echolalia (repetition of speech), need for routine/sameness, sensitivity to noise and light, sudden outburst of difficult behaviours, sleep disturbances and general failure to learn from experiences as other children would. 'His behaviour, where should I start. I guess in the early days he was just uncontrollable. I can show you videos where you would hardly be able to tell it's the same boy. He didn't really talk, scream yes... I'd take him to nursery and he'd pull or tear down displays these nice ladies had spent hours on. Shopping. He'd pull things off of shelves... It's different now that he's older of course. We've worked really hard on managing his behaviour and he doesn't do those things any more. Now I'm more worried about him being on his own all the time at school and his obsessions with things boys his age find most amusing. A nine year old into toddlers shows. That doesn't go down well. Even his own brother teases him about it' (Parent 4).

Importantly, the study also asked mothers to comment on what they felt were positive aspects of ASCs. With exception to one mother, all parents mentioned between one and five positive characteristics of ASCs. The most commonly reported traits were honesty, exceptional memory, innocence, easy going and lack of agenda. Furthermore, four mothers commented on how having a child with an ASC made them more aware of disability. 'I've always been quite open minded, you know, tried not to judge people but it's just made me think. I never used to really think about it. I'd see a child when I was out and about who looked different and think ahh, how sad. But now I know, I know that you can't always see it can you? It just makes you that much more considerate when you see a child or an adult acting strange who perhaps doesn't look very different from you or me' (Parent 11). 'L has a current um what um shall I call it, interest lets say, you see they change all the time in Transport for London. L likes to go on the Internet and look at all the tube maps for London so when we go anywhere, he can tell us exactly how to get there. I guess sometimes his interests can be really useful and what a phenomenal memory he has to remember all of tha . Much better than his last obsession with Mario (mother laughs).... In fact yes, his memory is amazing. Comes back to bite me in the bum too. You know he can remember what promises I made him, the date, the year. I should have been more careful about what I promised he could have when he's older (mother laughs)' (Parent 7).

The focus of literature and perhaps even professionals on the negative aspects of ASCs was mirrored in this study by mothers being thrown by the question 'what's good about having a child who is affected by an ASC?' Many mothers took time to think about this question or needed probing to think of anything else that was a desirable trait. This was not the case when mothers were discussing difficult child behaviours. This finding is likely to reflect that ASCs do present parents with a unique profile of stress, which is highly demanding. However, the fact that mothers took time to consider the positive attributes could also reflect the question having never been asked of them. Comments such as 'hum, gosh', 'oh I don't know, I've never really thought about it' along with long pauses reflect thought around the topic, implying little explicit consideration in the past.

For aspects of ASCs mothers noticed early on and are still finding challenging to mange, the findings of this study reflect those of the many studies in this area. Research has generally shown both parents and professionals notice delays in language development and lack of joint attention, difficult behaviours such as tantrums, need for routine and sleep disturbances, to name but a few characteristics associated with ASCs (e.g. see Zwaigenbaum, Bryson, Rogers, Roberts, Brian et al, 2005; Hastings & Brown, 2002). Furthermore, as demonstrated above, research has also shown that symptoms of ASCs change over time, as does parental understanding and recognition (Bailey, Phillips & Rutter, 1996; Stone & Hogan, 1993). The findings of this study are therefore consistent with others documenting the unique sources of stress for parents and families of children with ASCs. This study has however advanced knowledge of the unique aspects of the condition mothers feel should be cherished.

## 6.3.3 Maternal and family stress

The nature of ASCs and the fight to receive an appropriate diagnosis was associated with somewhat of an emotional rollercoaster for parents in the early years, made worse by the reactions of other family members. 'In my mother anyway it took a long time for her to accept it and she um she kept saying oh its normal behaviour for a 3 year old, which is so frustrating and annoying. I just had to go through it with her in stages and suddenly this last month she's started helping' (Parent 13).

Depending on the nature of the child's behaviour, mothers reported needing to make several adaptations to family life and often found themselves now structuring their family routine around their child. For two mothers, this was somewhat less stressful as their children did not have any siblings. 'He takes up most of my time. I can't work. When would I fit it in between speech and language appointments, occupational therapy and doing the school run? My life is a routine that is solely based around his needs. I don't mind that really. I've only got him and yes, he may not have turned out how I expected but I love him for who he is and I want to do my best for him (Parent 12).

Mothers did however report changing states of mind, moving between feelings of being able to cope and other times when they felt things were falling apart. 'Um it goes in phases, um sometimes I think everything is going really well and everything is settled but then I sort of get panic attacks when I think crumbs, what's it going to be like when he's 16 or what's going to happen when we're older. How is he going to exist as an adult?' (Parent 6). 'I'm constantly, there's constantly a new challenge and I'm, constantly having to think of new ways to deal with one challenge and then another. I'm glad she's not more severely affected and that I don't have any other children. I don't know how people with more than one child cope. I can work everything around R and I've got used to it but gosh, just imagine if I had another child. It's just a coincidence that I don't... Life is on an even keel for us and it all depends on what is happening with R.. So yes, constantly changing. We manage but that doesn't mean it's not tiring' (Parent 13).

Where siblings were present, mothers often had added guilt related to disproportionate amount of time devoted to the child affected by an ASC and or felt the added stress of problems within the sibling relationship. 'My eldest has autism, he's quite severely affected. He has no language. He's in a special school so for most of the day it's just me and the littlen, who as you can see, is under 3 (mother laughs). They're generally ok but P, say hello (talking to the child) doesn't really understand yet so he wants to play with his brother but he just pushes him away... He also doesn't like loud noises so gets upset when P cries or bangs his toys about. I'm usually ok because I don't have both of them 24-7 but the weekends can get very stressful (Parent 10).

An additional stressor for families, mentioned by all mothers, was a lack of understanding into ASCs by others, which often left the family feeling socially isolated. This included mothers commenting on how family members had questioned their parenting skills and how parents of other children they knew had stopped inviting them to events due to their child's disruptive behaviour. Some mothers also stated they themselves avoided socializing with others to avoid

problems caused by their child's behaviour. 'I can only really do things with very good friends of mine, and even they get annoyed from time to time... I mean it's not nice when your child hits someone younger because he couldn't just tell them to stop annoying him. If we're not in the room I can't even defend his behaviour because its most likely he did do it but it's about findings out why... My child is not nasty, he just isn't always able to control himself and other people, even with the best intensions, don't always understand that' (Parent 9).

Ten mothers were also married and commented on the impact of an ASC on their relationship with their spouse. There were mixed responses. Although all mothers felt their marital relationship was challenged by having a child with an ASC, there were also strengths in that in times of crisis, this brought the couple closer together. There was a sense of the couples fighting for their child together and showing strength as a family. 'My husband is my rock. I do tend to take on the responsibility for I but when I need A, he is always there, like for the really important meetings. I think initially it was hard for him and even now. He's a real manly man and loves his sport and I is not interested at all. I think A finds it hard to cope with that but he's found other things they can do together... I'd say the biggest struggle we have is with finance. I seem to always come up with wonderful new things that might be able to help J and none of it's cheap so we often find ourselves arguing over what's best in that sense... In the end though, we're both fighting for the same thing (Parent 10). 'I think it has caused a huge set of problems in our relationship to begin with most definitely. We still do actually, we probably have more problems with conflict in our marriage than we used to. Things like A is supposed to be looking after H and he gets toothpaste all across the floor and I would say why did you let him do that? And I am blaming him, we both do it to each other actually. It has been awful lot of conflict and last night he tipped tip-ex all over the floor.. But I think you get this amazing sense of we are doing this together and we do it for our children and that is where the strength has come from. On a day-to-day basis I think we moan and gripe more than we used to' (Parent 2).

Mothers who had separated from their partners since the birth of their child did not report this being due to stress related to raising their child. 'Since S was born I'm no longer with his dad. S obviously has very complex needs with having Down syndrome and autism and needs a lot of my time. I expect this sudden change in my time being devoted to S and not other relationships may have affected my marriage... To be honest though, even if S hadn't come along, I don't think I'd have still been with my husband. I guess in some ways, I always knew we weren't um well the best match' (Parent 12).

The final theme emerging within the data related to the sources of stress that is posed by schooling. Mothers with more severely affected children had somewhat better experiences where those with less severely affected children reported much stress related to dealing with schools. 'It's potluck, it really is. One year we get a teacher who really understands and the next I pick up a child who is screaming blue murder about how horrid the teacher is for taking tokens away... I think because he appears to be quite capable, sometimes his difficulties get forgotten and teachers are quick to misinterpret why he's doing something... You know of course a diagnosis is just the start. I'd imagine and, in fact I know from my support group work, that statementing is another struggle... It's just never ending' (Parent 11). The quantitative data from the RCT study showed that mothers in the FIT-DSD intervention group were experiencing very high levels of parenting stress. Furthermore, mothers were experiencing some feelings of depression and anxiety, although only one mother reported clinically relevant levels of psychological distress, as measured by the Thoughts and Feelings Scale. The interview data discussed above highlights the fact that the stress mothers experience related to parenting a child with an ASC is multifaceted. Mothers, and the family at large, not only experience difficulty in the early years in making sense of their child's behaviour and fighting for a diagnosis, but also contend with reactions of other family members who often find ways of explaining the child's behaviour as 'normal' for his or her age. When a diagnosis of an ASC is given, families are left to carry on with day-to-day life, and stress can be elevated when parents need to structure their life around their child's needs, which often leaves them feeling socially isolated. In

terms of the marital relationship, the study found mothers do report strain placed on their relationship, but that parenting a child with an ASC can also bring couples closer together. Where parents were separated or divorced, they did not attribute this to the difficulties in relationships brought about by stressors related to their child. Furthermore, mothers felt their sources of stress were constantly changing relating to schooling, worry about the future and so on, all of which also had an impact on their feelings of ability to cope. Taken together, the findings support past research that suggests the unique nature of ASCs is a major challenge for families to adapt to, which often results in social isolation, financial strain, problems in sibling and marital relationships, worry about the child's future, along with the daily hassles involved in managing the child's behaviour (e.g. see Gray, 2003; Koegel et al; 1992; Rivers & Stoneman, 2003; Sanders & Morgan, 1997). Nonetheless, it is important to note that despite this stress, mothers do find joys in their role as parenting a child with an ASC 'Totally, my whole 24 hours is, is just all depends on her. Everything is about her, the options I have are totally restricting for any thing. She's hard to deal with but its worth it for the satisfaction I feel for having her' (Parent 1).

## 6.3.4 Resources for coping

All mothers in this study reported some behaviours they had developed over time to cope with their stress. Twelve mothers reported regularly attending or having attended support groups in the past and found it useful to be in the company of others who could share their experiences. One mother also stated that she was heavily involved in her local church. This mother was the only one to state she did not want to attend support groups because she liked engaging in activities outside of the world of autism. 'I am the chairman of a committee, which is organizing a gift fair at the end of this month. Last year it raised a big amount of money, which is great considering I had to find time for it... It's something completely different and a situation I feel appreciated in. It literally gets me out of the house and I need that. I don't want to go out in the evening and talk about disability and hear about everyone else's problems (mother laughs)... I mean that's fair enough, some parents take the

other route which is to get involved with that kind of thing, which makes them feel that everybody there is in a similar situation and understands me' (Parent 2).

Mothers also found where good social support was available, this was extremely helpful. 'My main strategy is my mother-in-law who is amazing and she has R for 24 hours every week, which is a good long period of time and it means I can carry on with singing in the choir, which is a great love of mine and go out for a night with my husband' (Parent 13).

Mothers also found recreational activities important such as going out shopping and treating themselves to even just a hot bath. 'On the odd chance I do get sometime to myself I do like to treat myself by going shopping with the girls, without any children pulling at my feet. The weekly trip to Sainsbury's doesn't really count... I have to make sure I've got good childcare in place though.. My husband can't cope for more than a few hours on his own' (Parent 6). 'Have a lovely hot bath, which I haven't got at the moment, I have got no hot water so it's a luke warm bath, which is revolting. But a lovely bath with a glass of wine and a book' (Parent 3).

Four mothers also mentioned their personality as helping them cope. 'I'm not the sort of person who focuses on the negative really. I think it's important to focus on the positive and get through it and I suppose I have to be like that if I'm helping others too… I have I should mention got a book though. I've made like a scrapbook of L's life where I add in all his achievements. If I ever feel down, I open it up and I can see how much progress he's made and that soon gets me back in the right frame of mind' (Parent 7).

Two mothers were also using respite care, which was found to be effective where other mothers did comment on the lack of support they received from services. ' We used to have a nursery nurse who came in I think once a week to play with him. Of course that stopped when he hit 5. Helpful while it lasted but then all of a sudden, you're on your own again' (Parent 5).

Mothers in this study, despite their very high levels of parenting stress on entering the RCT, already had ways of coping with their life stress. This included, as research has suggested, relying on good social support and respite care (Boyd, 2002; Factor, Perry & Freeman, 1990). The study also supported the role of maternal personality in helping mothers cope, and this has also been found elsewhere. For example, those with hardy personalities tend to cope better with raising a child with an ASC (Weiss, 2002). The study also found that mothers were generally unhappy with the lack of services they received to help them as their child got older, although they acknowledged that these were most helpful when on offer. What should not be underestimated, however, is the importance of mothers having time for themselves. As all of the mothers in this study had taken on the majority of tasks related to childcare, they felt even small things such as the occasional shopping trip, a night out, reading a book or taking a bath could also help them cope with the daily hassles they experienced.

#### 6.3.5 The FIT-DSD Intervention

Six mothers in this study stated they had not expected that the FIT-DSD intervention would benefit them. 'I hope you don't mind be being honest but when you first came to see me and gave me these cards, I thought oh no, its not a real intervention is it? How is shopping somewhere different going to help me? That showed me though' (mother laughs) (Parent 4).

There were mixed responses to which aspects of the intervention mothers found useful, although twelve mothers noted feeling more positive within themselves having taken part in the study and felt the intervention itself was well suited for them to engage with. Some mothers found both sets of intervention resources – expander and disrupter cards- useful. Some found themselves orientating more towards the expander or the disrupter cards. 'Using the cards was easy and I thought it was a great little idea to put them together on that clip, that was really nice. Sometimes I couldn't always do one of the cards but then it was easy enough for me to

flip through and find one I can. I suppose then I did feel a bit guilty for not doing the first one. I did prefer the cards that were more specific like shop in a different supermarket or speak to your child in a different accent. I didn't really like the ones that said be more or less assertive, that was too wishey washey for me. Maybe say be assertive 3 times today?' (Parent 13).

'I did something different everyday, listen to the radio and sometimes I'd need to prepare for things which I was quite excited about like cooking. The best thing was to run through one in the morning and as soon a I feel stress I'd go through it in my brain. I'm at home all day and after listening to the radio for 5 years now it's a bit boring to me and um, it's quite a depressing channel, which I didn't realize. So now I'm listening to Radio One and it's fantastic. When I listen to it I think I'm 16 again and the commentator is really cheerful and funny so I've carried on with that' (Parent 11).

Mothers felt the FIT-DSD expander cards in particular were useful because they broke up their day and provided opportunity for something new. 'You know, you're not telling me to get up and go to the Caribbean. Its something small and achievable in your day and a break from that rut that's life... Um (long pause in speech), it made me think god, my whole day is like a list that I tick things off of... Just taking that time out for me made me enjoy my day a lot more and I think it's helped my relationship with my children too. I mean I actually sat and watched a cartoon the other day and they enjoyed that time with mum (Parent 9). 'I think doing something different everyday was a very good because it um focused your energy on something different. I think anything fresh and new somehow brings a positiveness to you and your day and I can't tell you how many things happen, whether it's luck, fate because I had an aura around me because I made it happen whatever it, I don't know but positive things came' (Parent 3).

Three mothers also commented on why they felt the expander cards and the small change in their daily routines helped reduce the level of stress they experienced. 'I think it puts you in control (referring to the intervention). It gives you the tools and permission to be in control of yourself. It makes you think that you're not just the mum of a child who has problems...It makes you think I'm an individual. I can take time out for myself and be a good parent. I genuinely feel happier and calmer within myself because I have the confidence to take time out for me. I'm not worrying about being a mum all the time and I think as a result of this, better things are happening.' (Parent 5).

The disrupter cards however were thought to be effective because of the increasing awareness mothers had about their levels of stress and the time out they needed to gain perspective. 'It (referring to the intervention) made me more aware of when I was stressed. That was a real eye opener for me to stop and think how I was feeling and that self-awareness has really helped me. The blue cards (referring to the disrupter cards) especially take you out of a situation for long enough to get some perspective. Like when I was sitting in the car, feeling my heart racing before a meeting with school, and I clapped the only tune that came into my head, humpty dumpty. How ridiculous. That made me laugh but then that helped release the tension and I thought, you know what, what's the worse that could happen?' (Parent 6). 'They just snap you out for long enough to come back with a different approach... I tried using an accent. I think the first time it worked because he just looked at me as though I was mad. Not so effective next time but um yeah, it definitely makes, makes you think about how you deal with situations... I did get a bit stuck when we were having a tantrum in a shop and I didn't have my cards with me. Oh, I can't remember what it was now, um, anyhow I thought of something myself but I was much calmer and for a change, I just focused on him and getting out into the car and not what everyone else was thinking... That is really not like me' (Parent 13).

Four mothers also commented on how their partner had noticed a change in them 'Since I've stopped using the cards I can feel myself getting worked up a lot more and it was funny because the other day, I can't remember what I was moaning about, and my husband said, where are those damn cards, you were much nicer on them (mother laughs)... So I've started using them again. I even took them to the support group to show some of my friends' (Parent 5).

Only one mother did not feel any benefit of taking part in the intervention, although she agreed she thought it could help others. 'I think to begin with I was quite enthusiastic about it as one always is with these things. I think it just became, I was just too busy and my mind was on other things and it just didn't come naturally to me to look at cards when I was really stressed. It just never came into my mind because I was so kind of retrenched in the situation. I'm not saying it wouldn't work, and I'm sure it would. I think everything in there is fantastic and I would agree with it. I just thought why am I doing this? I knew it was for your research but I am so un-routine anyway and I am constantly doing different things anyway '(Parent 2). Despite the thoughts of this mother towards the FIT-DSD intervention, results from study four suggested that the mother may have benefit from having taken part in the intervention. For example, the mother reported less parenting stress at follow-up. The mother's score in total parenting stress, as measured by the Parenting Stress Index- Short Form, was 84 on entering the study and was 75 on completion. Additionally, the mother perceived her marital relationship better at follow-up. The mother's score on the Relationship Assessment Scale was 15 on entering the study and 25 on completion. The largest effect of intervention was on the reported use of family coping strategies. On entering the study, the mother reported her family as using a limited number of strategies to cope with problems, as indicated by a low total score of 44 on the Family Crisis Oriented Personal Evaluation Scales. This score was equal to 128 at follow-up, suggesting a large change in family coping behaviours. Although the mother reported low levels of depression on entering the study, the intervention helped her in managing levels of anxiety. At the start of the RCT, the mother scored in the marginal range for anxiety. At follow-up, the mother

reported scores in anxiety falling within the normal range of the Thoughts and Feelings Scale. There were also several changes across scores on FIT variables, which showed the mother was improving in her profile of personal strengths. The mother did engage with the intervention and attempted 24 tasks over the course of the RCT study. This makes it difficult to determine whether the benefits noted were due to the intervention, or other contributing factors.

The data above suggests that for the majority of mothers, the FIT-DSD intervention was an effective way to help manage stress in the context of parenting a child with an ASC. In general, mothers perceived that the intervention was effective for three reasons:

- 1. It gave mothers permission to take time out for themselves, which helped break up their daily routine.
- 2. It made mothers more aware of when they were feeling stressed.
- 3. It gave mothers time out from stressful situations, which allowed them to come back with a fresh perspective.

The intervention therefore supports the idea that mothers can be encouraged to manage their own stress with relatively little training. The data also suggests that the intervention encourages mothers to think flexibility as many commented on how not having the cards available in a situation made them generate their on Do Something Different tasks. Additionally, the experiences of mothers with the intervention indicate that due to minimal training and the format of the intervention itself, mothers found it well-suited to their needs, and some of the experiences of mothers have pointed to ways in which the tasks themselves can be modified.

#### 6.4. Discussion

This study aimed to provide insights into mother's views of how raising a child with an ASC affects family life. Past research in this area has delineated several stressors families contend with. Nonetheless, qualitative investigation of these stressors has been scarce (Midence & O'Neill, 1999). This study reported on individual interviews carried out with thirteen mothers who took part in the RCT of the FIT-DSD intervention. The aim of the study was to find out more about how mothers feel about raising a child with an ASC. Furthermore, the study drew on methods from grounded theory to identify the relationship between themes arising within the raw data. This allowed elaboration on the journey mothers went through from the birth of their child to diagnosis and day-to-day parenting; leading into the potential of the FIT-DSD intervention as an effective resource for managing stress.

Five themes arouse from the data and the relationships between them has been summarized in figure 6.1 and discussed in section 6.3. Overall, the study supported the research literature showing:

- 1. Parents generally realize their child is not developing typically before the child's  $3^{\rm rd}$  birthday.
- 2. The process of obtaining a diagnosis is extremely frustrating and challenging emotionally.
- 3. When a diagnosis is received mothers often experience increased emotional turmoil in coming to terms with the impact of diagnosis on the future.
- 4. Day-to-day life is a constant struggle for mothers where their stress is multifaceted. This study has highlighted stress related to impact on inter and external family relationships, financial strain, struggle with a lack of understanding from others and difficulty in managing challenging and changing child behaviours.

The study has also shown that mothers receive much satisfaction in their role as a parent and in fact should be encouraged to think about the attributes of ASCs that make their child wonderfully unique. The study has also tentatively pointed to areas of service that might benefit from improvement, including the need for more awareness in different health professionals and single centre, multi-disciplinary assessments for diagnosis. Whilst this study only reports on the experience of thirteen mothers, there is much data available across different studies to support the need to improve diagnostic procedures and help families manage stress (e.g. see Baird, Cass & Slonims, 2003; Howlin & Asgharian, 1999; Midence & O'Neil, 1999).

Despite the stress related to raising a child with an ASC, this study has most importantly shown that parents need to be encouraged to take time out for themselves to engage in recreational activities. The experience of mothers in this study shows that parenting a child with an ASC often forces them to develop routines that become entrenched. Whilst this helps them manage their role as a parent, this can add to levels of stress. The study has shown that by disrupting the habitual behaviours of mothers, they can feel better within themselves and more confident in taking time out for 'self-care'. The benefits of such habit breaking extend further than the way mothers feel within themselves as evidenced by some of the mothers commenting on how their spouse had seen positive changes within them. Taken together with the results of the RCT, this suggests that by disrupting habits, the FIT-DSD intervention is a powerful resource to help mothers manage the stress of raising a child with an ASC. Furthermore, the study has pointed to how the intervention can be enhanced to be even more effective, including instructions of how mothers can take on board the principles of the intervention in times where the resources are not to hand. Some of the comments of mothers will also help with the development of the new tasks.

Qualitative investigation of the experiences of mothers with the intervention has also shed more light on the processes behind why the intervention is effective. This richness of data was not achieved within the RCT study. Whilst the RCT study showed enhancing Self-responsibility in mothers is associated with beneficial changes in parenting stress, this study demonstrated that mothers are specifically gaining responsibility for self-care. Mothers in this study felt they had lost their identity as an individual and the intervention helped them realize how taking a little time a day for themselves could make them feel very different. Additionally, the disrupter cards helped mothers really consider the types of situations that caused them stressed. This self-awareness is likely to feed into coping mechanisms, thus facilitating the process of tackling the problems mothers face.

The comments of four mothers in relation to what they had expected of the intervention suggests it is unlikely that the positive effects of intervention are due to a 'self-fulfilling prophecy'. Furthermore, one mother in the study stated that although she felt the intervention was a good idea, it was not suited to her 'personality', although there was some evidence in study four that the mother had benefit from the intervention. This suggests that mothers were indeed open with the researcher about their experiences, as evidenced in the many accounts that were given of specific examples of tasks mothers had enjoyed and strategies for coping with stress from the disrupter cards used in stressful encounters. Grounded theory was also used to explore the experiences of mothers. This approach to qualitative research is based on the fundamental assumption that the resultant theory of people's attitudes, thoughts, feelings and experiences will emerge from the data alone and not the pre-conceived ideas of the researchers. It is therefore unlikely that the experiences of mothers reflect expectations about the intervention and or the intensions of the researcher.

No one child with an ASC is the same and therefore the experience of each mother is unique. Parent training relying on the development of knowledge and ability to mange child behaviour is undoubtedly a useful resource for this group who experience exceptionally challenging and chronic life stressors and daily hassles. This programme of research does however remind professionals to pay due attention to promoting self-care in mothers also. This research has clearly shown that when mothers engage in breaking their usual patterns of behaviour, this has many benefits including greater awareness of stress, less parenting and psychological distress, better feelings towards their partner and a general sense of calm and ability to cope. Such benefits can be achieved in an easy to administer, cost effective and engaging intervention that requires minimal 'training' in the intervention techniques.

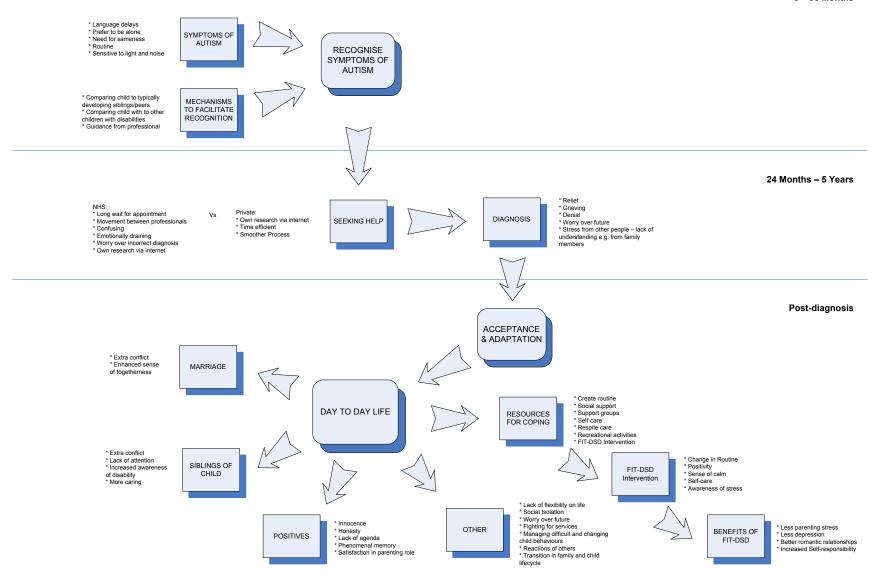


Figure 6.1. Grounded theory analysis of maternal experiences: Pre to post diagnosis

## Chapter 7

#### **General Discussion**

This general discussion will begin with an overview of the aims and findings of this thesis. It will then draw out some of the broader issues raised by the research, focusing on three pertinent questions:

- 1. What the programme of research has added to understanding the correlates of family functioning?
  - a. What do FIT variables contribute to the study of family functioning?
  - b. Why is it useful to measure family habits?
- 2. How the research has advanced knowledge of interventions aimed at improving how mothers experience the family?
  - a. Why do family interventions need to tackle the 'habit web'?
  - b. What was the active ingredient in the FIT-DSD intervention?
- 3. What the research has contributed to general understanding of family functioning in units with a member affected by an ASC?

#### 7.1. Overview

## 7.1.1 What do we know about family functioning?

The way in which a family functions can have far-reaching consequences for its members, even impacting upon their physical and psychological health. Psychologists have therefore sought to identify what typifies family functioning. This has led to many academic models being advanced to delineate characteristics of functional families (e.g. Epstein et al, 1978; McCubbin & Patterson, 1981; Olson et al, 1989). Each of these has added to understanding of the number of sometimes complex variables that influence family life. The models advanced have also yielded a range of different instruments for measuring family functioning (e.g. Miller et al, 1985; Olson, Portner & Bell, 1992). These have been extensively employed to produce reliable and objective data on family functioning. They have also sought to investigate the association between perceptions of family functioning, as measured by the instruments, and personal outcomes of family members. This includes

exploring the association between perceptions of family functioning and mental health (Schudlich, Youngstrom, Calabrese & Findling, 2008), self-care in chronic illnesses (Spezia & Chang, 2007), and risk of suicidal behaviour (Chen, Wu & Bond, 2009). Finally, and perhaps more importantly, these instruments have allowed clinicians to identify and intervene with families experiencing problems due to poor functioning.

The many models that have tried to highlight characteristics of functional families suggest that family functioning is multifaceted and difficult to define. For example, the McMaster Model includes six dimensions of family functioning. The Circumplex Model of Marital and Family Systems (Olson et al, 1979) includes three central dimensions (cohesion, adaptability and communication). Whilst the models share some theoretical synergies, each has advanced a unique perspective on the characteristics of families that work well. Generally, however, these models have not given sufficient weight to the fact that families are made up of individuals, each of whom is likely to hold different constructions of family problems, and each of which may have different resources for coping with these problems. The models of family functioning have done an excellent job in outlining the general contextual factors in families that define and influence functioning. The research outlined in this thesis suggests that they may not however have adequately captured important individual differences between family members, nor the individual characteristics that might affect functioning and outcomes. As Heatherington et al (1998) recognize 'in a family, each person has a story that is individual, personal, and private. Nonetheless, family members' constructions have a powerful influence on their interactions with each other, at home as well as in the therapeutic setting' (p.3).

## 7.1.2 Aims and findings of the research

This programme of research addressed the shortcomings of previous studies by exploring the characteristics of individual family members that might mediate their perceptions of family functioning. These characteristics, or individual differences, were posited to be closely related to effective coping with family problems. It was hypothesized that they may also account for why people in the same situation perceive their circumstances very differently and experience very different outcomes. Specifically, the thesis explored whether the differences between individuals, as measured using FIT Science variables, account for variations in how people perceive their family functioning. In other words, family functioning is not objectively measured but seen through the eyes of its members, and each of those members adopts a different viewing 'filter'.

The individual studies that were carried out resulted in a number of novel findings, which have implications for understanding how people perceive their families. Furthermore, the findings are of applied value for intervening with individuals to improve perceptions of family life. In summary, the main findings were that:

- 1. Important personal strengths, as measured by FIT variables, do predict perceptions of family functioning.
- 2. FIT variables, which reflect individual differences, are related to the types of habits present in family life.
- 3. FIT variables mediate the relationship between aspects of family functioning and levels of depression and anxiety.
- 4. FIT variables predict how mothers of typically developing children, and children with ASCs, perceive their family functioning and levels of parenting stress.
- 5. An intervention, based on FIT Science, can be effective in helping mothers of children with ASCs improve their perceptions of family life and their own levels of parenting and personal stress.

## 7.2. Contribution to understanding family functioning

# 7.2.1 Individual differences in perceptions of family functioning

A repeated finding across studies one, two and three was that people scoring high on FIT variables perceived their families as functioning effectively in areas of the McMaster Model. This finding has two important implications. First, the results suggest that a person's cognitive and behavioural characteristics influence perceptions of the family. Differences in scores on FIT variables account, in part, for why some people perceive their families as functioning effectively, whilst others do not. A central question arising from these findings is why would people scoring high on FIT variables perceive their family more positively? What personal strengths are captured by FIT variables that make family functioning a more positive experience for individuals?

Chapter one explored some of the reasons a person scoring high on FIT variables might have a better experience of family life. The results of the studies that were carried out supported these suggestions, finding that cognitive FIT variables are closely related to perceptions of the family. Of course, because the studies relied on correlation analyses, it is difficult to determine cause and effect. It may be that families that function effectively allow for the personal development of members. On the other hand, people scoring high on the Constancies may view the world more appropriately and consequently use effective strategies to cope with situations. It may be that scoring high on the Constancies therefore facilitates effective family functioning.

To try and address this issue of 'cause and effect', in studies two and three, participants were recruited from three unique groups. The groups were adults with ASCs, mothers of children with ASCs, and mothers of children in the 'terrible-twos'. The inclusion of mothers of children with ASCs was particularly insightful. There is much evidence of contextual and environmental variables making family functioning a negative experience for families with a member affected by an ASC (e.g. Rao & Beidel, 2009). Many research studies have therefore investigated the role

of coping strategies in family adjustment to ASCs. Glidden, Billings & Jobe (2006) stated that studies have however failed to explore why some families cope better than others? Although it is apparent that certain types of coping strategies facilitate adjustment, what determines the differences between family coping styles? Study three provided some useful insights into this question.

In study three, involving mothers, the results of regression analyses showed that scores on FIT variables independently predict parental stress and are related to perceptions of family functioning. These findings suggest that differences on FIT variables explain why some people cope better with their circumstances. Mothers of children with ASCs encounter many external sources of stress. This was evidenced in study three by high levels of parental stress resulting from the autistic child's behaviour. Despite stress in the environment (e.g. the child), mothers scoring high on FIT variables reported coping better. This is strong evidence to suggest that independent of environmental constraints, scoring high on FIT variables facilitates coping. FIT variables are not a measure of coping styles but measure a person's capacity to cope effectively. It is therefore inferred from the findings that despite akin stressors (i.e. a child with an ASC), mothers with high scores on FIT variables possess the type of thinking and behaviours that allow them to be resilient. This resilience will include the use of more effective coping strategies, better family communication, and so on. It is likely that people scoring high on FIT variables facilitate effective family functioning, rather than family functioning typifying a person's scores on FIT variables.

The implications of the findings are that characteristics of the person, regardless of environmental or contextual constraints, influence outcomes. Therefore, there may be value in further exploring the correlates of variables such as the Constancies, given that the Constancies play an important role in how people interpret and experience events. Behavioural Flexibility, although important, was not consistently related to outcomes such as perceptions of family functioning. It would therefore seem more appropriate to explore factors that are related to how people make

sense of the situations they encounter. For example, one area that may be worth exploring is the association between personal construing, as defined by Personal Construct Psychology, and scores on the Constancies. Personal Construct Psychology is interested in exploring the cognitive constructs people develop to help them understand the world (Francella, 2003). These constructs are believed to guide how a person sees the world around and interprets experiences. If an experience does not fit a person's construct, the construct may need to be modified (Francella, 2003). It may be that a person scoring high on the Constancies has more appropriate constructs of the world and is more flexible in adapting constructs in response to new experiences. In the context of the family, this may translate into a person who has a positive experience of the family being characterized by flexible construing, and high scores on the Constancies. Flexibility in the filter from which a person views the world might facilitate adjustment to different situations. As a next step, it seems useful for future research to focus on understanding why the Constancies in particular are associated with positive experiences?

## 7.2.1.1 Measuring family functioning

The second implication arising from using FIT variables to study family functioning relates to the use of measures such as the Family Assessment Device. The findings in this thesis suggest that measuring family functioning through self-report scales may not provide an accurate picture of family life. Scores on measures such as the Family Assessment Device might be contaminated by a person's own 'version of events', rather than reflect what is objectively going on in the family. The 'version of events' itself depends on scores on FIT variables. In this way, scores on assessment tools might simply reflect a person's profile of cognitive and behavioural resources for coping. Would it therefore be more appropriate to use the Family Assessment Device to identify individuals who may not possess characteristics to contribute effectively to the family? In the main, scores on assessment tools have been used to identify families experiencing difficulties in specific areas of functioning. This research suggests that assessment tools might actually be signally the state of a person's ability to function effectively in the family. The findings have some

interesting insights for clinicians and researchers when administering and interpreting what scores on assessment tools actually mean. Rather than using such scales as an indication of families in which there are 'problems', the scales could be screening people who cannot 'cope' with family life, or who have distorted perceptions of reality. Research using methods developed from areas such as Personal Construct Psychology might help explore whether scores on the Family Assessment Device do in fact reflect the filter from which a person is viewing the world. Francella (2003) states that even the most routine occurrences may seem entirely different because of a person's constructions. This is in line with Fletcher and Stead's (2000) suggestion that the Constancies determine how people make sense of the situations they encounter. A broader issue arising from this research is whether it is possible to truly measure family functioning if perceptions of reality are coloured by cognitions? To fully answer this question, it will be necessary to understand the association between the Constancies, other measures of cognitions (e.g. constructs) and scores on the Family Assessment Device. This thesis, as a starting point, has suggested that interpreting results on self-report measures comes with the caveat that scores may not reflect reality. People can be inventive in the way they perceive situations. FIT variables are one correlate of people's experiences of the family and research will benefit from further exploring factors that shape the perceptions of individuals. The study of contextual factors, although useful, only offers part of the picture as to why there are differences in how people experience the family.

## 7.2.2 Family functioning and family habits

This thesis, to the researchers knowledge, was the first to draw on the concept of habit to explore the determinants of family functioning. The Family Habit Assessment Tool was developed to extend the applied value of measures such as the Family Assessment Device. Responses to items from the Family Assessment Device provide a snap shot of the types of difficulties a person perceives in the family e.g. there are problems in 'communication'. The Family Habit Assessment Tool, on the other hand, was designed to break down problems in 'communication'. This was

achieved by the habit scales providing a hierarchy of 'problem' behaviours that need to be tackled or behaviours that might need support to be maintained.

In reference to the habit scales, the thesis suggests that the concept of measuring family habits is of value. The correlations reported in studies one and three between family habit measures and scores on the Family Assessment Device were not high. This suggests that the Family Assessment Device and Family Habit Assessment Tool are measuring different constructs. Study two suggested that the habit scales might not function in this way for adults with ASCs. At least in the general population, the habit scales appear to be functioning as intended by differentiating perceptions of family functioning from actual family behaviours.

The results of studies one and three showed that people who have a positive experience of the family report more effective and fewer ineffective family habits. These findings suggest that the frequency of occurrence and level of control over day-to-day family behaviours are very important to consider. Whilst it is useful to use the Family Assessment Device to identify where problems exist e.g. in communication, it is also useful to know which family behaviours contribute to these problems. For example, avoiding discussing fears and concerns is more of a frequently occurring problem than discussing general thoughts and feelings. Although the habit scales have done a good job in attempting to measure family habits, the scales will benefit from being developed further. The habit scales were based on the general functioning scale from the Family Assessment Device. As such, the scales were limited in the scope of family habits measured. For example, a family may be experiencing difficulty in 'communication'. There are likely to be many behaviours that contribute to this problem e.g. people dismissing the views of others, people talking over each other, and so on. The habit scales did not measure these 'micro' behaviours and were focused at a 'macro' level of assessment of family habits e.g. how frequently people avoid discussing fears and concerns. It would be useful to extend the scales to explore the small behaviours that lead to problems in domains of family functioning.

Cunningham, Shamblen, Barbee & Ault (2005) reported research on 'social allergens' that could inform the development of an extended measure of family habits. A social allergy refers to a reaction, usually annoyance, to a repeated behaviour by a target e.g. a romantic partner (Cunningham et al, 2005). In effect, a social allergy occurs in response to a habit, which seems tolerable at first, but overtime, evokes an extreme reaction in the observer. An example could be something such as family member always squeezing a toothpaste tube from the top, or always leaving the toilet seat up. On the first encounter, these types of habits may seem slightly annoying. Cunningham et al (2005) demonstrated that social allergens become increasingly more intense overtime and influence perceptions of e.g. satisfaction in a relationship. Cunningham et al's (2005) research may be particularly relevant to the study of family functioning and factors that contribute to perceptions of family life. For example, it might be that social allergens add up to cause issues in areas measured by the Family Assessment Device. It would be very useful to develop the habit scales further to include behaviours that are not part of established measures of family functioning. Established measures tend to focus on contextual factors such as communication styles, emotional expression and so on. The measurement of real behaviours that contribute to problems in the family would be more informative for working with families. Cunningham et al (2005) were able to usefully measure social allergens in romantic relationships by asking people to rate how frequently a behaviour was seen from a partner e.g. shows a lack of concern for being clean, flirts with members of the opposite sex. Such measurement of family allergens is also recommended, based on this thesis having shown that family habits are related to the perceptions of individuals.

It is also worth further exploring the role of habits in how people perceive their families because habits may be a barrier to change. Intentions to do not always translate into real behaviour change (Sheeran, 2002). In fact, Webb and Sheeran (2006) carried out a meta-analysis exploring whether behavioural intentions lead to behavioural change? The researchers found that a large change in people's intensions resulted in only a small change in actual behaviour (Webb & Sheeran,

2006). In the context of the family, this means that a person who intends to change his or her style of communicating with others, may find it very difficult to overcome past habits. This is of course at a 'macro level'. The 'macro' goal being to change communicative style. Breaking this behaviour down, the person might also have trouble changing small behaviours such as 'not cutting people off when they are talking, not being critical of other people's opinions'. There is a lot of evidence showing that because of their automated and unconscious nature, habits are very difficult for people to overcome and can constrain people in all sorts of ways (Ouellette & Wood, 1998; Webb, Sheeran & Luszcynska, 2009). At the same time, research such as that by Cunningham et al (2005), suggests that people's habits, intentional or not, often cause problems in social domains. No research has looked at how family habits constrain people's perceptions of the unit and ability to change. Given research in the field of behavioural change and habits more broadly, it seems highly likely that habits will also constrain beneficial change in the family. A rigorous measure of family habits would help identify barriers to change and may also be useful to screen for issues in families before functioning is affected i.e. because like social allergens, the small habits of family members are likely to lead to bigger problems overtime. The development of such a tool would also help further explore the precise relationship between behaving appropriately and scores on FIT variables. This thesis suggested that FIT variables are specifically related to the development of effective family habits. The association between FIT variables and ineffective family habits was not statically supported, although there was a trend in the right direction. A more comprehensive measure of family habits would help explore whether or not family habits determine functioning in areas of established models and whether or not scores on FIT variables facilitate the development of effective behaviours in the family?

## 7.3 Intervening to improve family functioning

# 7.3.1 The FIT-Do Something Different intervention and the habit web

An important aim of this research was to explore the benefits of an intervention based on FIT Science for mothers of children with ASCs. This included the impact of intervention on perceptions of family functioning and levels of parenting and personal stress. The research also sought to explore whether the intervention would help mothers in developing their use of coping strategies, and improve perceptions of romantic relationships. Studies four and five, which reported on the outcomes of the RCT of a FIT-DSD intervention, demonstrated that the intervention had several benefits for mothers. The most profound effect of the intervention was on perceptions of parenting stress. There were also benefits reflected in maternal levels of depression, and satisfaction in a romantic relationship. The results of the intervention suggest that FIT Science may offer a theoretical framework to inform the design of interventions in contexts such as the family.

The majority of problems experienced by a family could either be understood in terms of interactions between family members or due to the psychology of the individual. Robin & Foster (2003) suggest that depending on the view taken, there are very different implications for intervening, namely whether an intervention should focus on the individual or take a systems approach. In several different areas, researchers have compared the outcomes of family versus individual approaches to beneficial change. These studies have had mixed results in relation to which type of intervention is most effective in helping people with the problems they encounter (e.g. Brent et al, 1997; Eisler et al, 1997). Stoddart (1999) suggested that the approach selected needs to be tailored to the family member or members who are most affected and willing to try and address their problems.

The FIT-DSD intervention, as an individual approach, seems particularly useful for mothers of children with ASCs. In families with a member affected by an ASC, mothers are often the focus of research studies, with studies consistently finding that mothers report many problems in areas such as family functioning and

parenting stress. This focus on the outcomes of mothers stems from the assumption that mothers assume most responsibility for childcare, as supported by the qualitative accounts in study five.

Previous interventions designed to help mothers of children with ASCs have been aimed at improving perceptions in problem areas by adopting skills training. The limitations of this type of approach were discussed in study four. In the main, interventions utilizing skills training are predicted on the assumption that a generic set of skills can be imposed upon a homogeneous set of parents. The reality is that the skill gaps, individual characteristics, and circumstances of the parents vary enormously and limit the benefits of training. For example, skills training might help parents deal with one type of child behaviour problem, such as managing aggressive behaviour. The strategies used in this situation may not be as useful for a parent in future when trying to manage self-stimulating behaviour. This may result in a 'changing', rather than 'closing' gap in skills. The skills set, whilst useful, does not also address broader issues within the family that impact functioning. This might, for example, include problems in the marital relationship. Finally, Verplanken and Wood (2006) suggest that the goal of most, if not all interventions, is to bring about behaviour change. This inherently means replacing old habits with more effective behaviours (Verplanken & Wood, 2006). Skills training interventions try to do this without tackling the habit web. It is likely that even with the best intentions to implement training, parents will struggle to bring about real change in their behaviours because of the resilience of habits to change (e.g. see Webb and Sheeran, 2006). The consequences of the limitations of skills training are that parents might invest a lot of time and effort into engaging with training and see limited benefits. Benefits are limited by the relevance of strategies for the problem types parents encounter, and the behavioural constraints preventing parents from using their 'new skills'.

The FIT-DSD intervention was designed to overcome some of the limitations of skills training interventions, primarily by tackling the habit web. The FIT-DSD intervention directly addressed the habit web by expanding a mother's repertoire of behaviours and disrupting problematic behaviours and cognitions. Enhanced flexibility in thinking and behaviour, as demonstrated throughout this thesis, and by Fletcher and colleagues, has several benefits for individuals. This includes reduced levels of depression and anxiety (Hanson, 2008) and changes in health behaviours (Fletcher et al, 2010). By tackling habits, a person is given the opportunity to explore new strategies for dealing with problems and this often results in better outcomes and positive emotional experiences. This was demonstrated in the qualitative accounts of mothers in study five. Mothers commented on how both expanding and disrupting behavioural habits allowed them to approach a problem or situation with a new perspective and new strategies for managing stress. Selfgenerated change often also resulted in enhanced feelings of self-esteem and self-efficacy.

Additionally, by reducing tendency to rely on habits, the intervention was able to help mothers at different stages of the child's life cycle, and perhaps more importantly, with a range of problem types. The FIT-DSD intervention broadly addresses the habit web i.e. it is not confined to a particular problem type such as controlling child behaviour at meal times. In skills training interventions parents work on specific problems they have and might not see the relevance of strategies learnt to manage one problem type for another. If the relevance of strategies is seen, the triggers for behavioural responses may be different across situations and so learning is constrained by a change in habitual 'cues'. The FIT-DSD intervention, through expanding cognitive and behavioural flexibility, aims to allow the person to see things from a new perspective and with enhanced behavioural resources, Self-responsibly, Awareness, Fearlessness and so on. In this context, a generic tackling of the habit web is effective in using the person as the driver of change. That is to say that because a person is no longer constrained by habits, he or she is able to use appropriate thinking and behavioural resources to cope with different problem

types. It is therefore expected that the FIT-DSD intervention will help people with beneficial change across different areas of life. In studies four and five, this was demonstrated by mothers improving in their levels of depression, parental stress and improved perceptions of relationship satisfaction.

# 7.3.2 What was the active ingredient in the FIT-Do Something Different intervention?

A pertinent question arising from the results of studies four and five relates to understanding what the active ingredient was in the intervention? Why does the FIT-DSD intervention help mothers in managing parental stress, depression and in improving perceptions of romantic relationships? There are three plausible answers to this question, which will be discussed below.

In reference to parental stress, the area of biggest improvement, study four found that enhanced levels of Self-responsibility were associated with the degree of benefit reported. This suggests that Self-responsibility is an important factor in promoting resilience in mothers. The definition of Self-responsibility given in chapter one demonstrates that this Constancy captures the extent of responsibility a person takes over what happens in life. It is expected that gaining Self-responsibility resulted in the enhanced self-efficacy, self-esteem and gaining of control over situations mothers reported in study five. If a person feels as though he or she is, to an extent, responsible for and has control over life events, it would be expected that confidence in ability to cope will be enhanced. Feelings of self-efficacy and control, as suggested by several other studies, facilitate family adjustment to disability (Lightsey & Sweeney, 2008; Lloyd & Hastings, 2009). It would therefore be useful to test empirically if Self-responsibility promotes self-efficacy and is associated with e.g. an internal locus of control. This would provide further evidence of the mechanisms involved in the success of the FIT-DSD intervention. From the results of studies four and five, it seems likely that Self-responsibility leads to many of the benefits mothers reported. The proposed associations will benefit from further empirical testing.

It is also possible that the tailored nature of the intervention contributed to its success with this particular group. Although mothers were given instructions about how to use the intervention resources and generic activities to engage with, ultimately, it was for them to decide when and how to use the specific tasks. In this way, the intervention was personal to each mother. The resources could be used in situations that triggered specific feelings for mothers and mothers had autonomy in selecting tasks that they were motivated to carryout. This may have created the sense of control that many mothers reported in qualitative follow-up in study five. Creating a sense of autonomy might be a key factor in the successfulness of the intervention, which can often be lost when people are guided by their behavioural habits. Adriaanse, de Ridder and de Wit (2008) also suggest that personal tailoring is important in facilitating behavioural change. In study five, mothers were not specially asked about their thoughts and feelings towards being able to select tasks rather than being prescribed a specific programme. This makes it difficult to understand whether personal tailoring is important for interventions with mothers of children with ASCs and for the FIT-DSD intervention more broadly. A study comparing a fixed DSD intervention to a flexible programme may help address the importance of personal tailoring.

Finally, it is also possible that the intervention did not directly result in changes in parental stress and relationship satisfaction. It may be that through helping mothers tackle their levels of depression, the intervention brought about a re-evaluation of perceptions. Depression is generally thought to be associated with distorted perceptions of reality, specifically pessimistic perceptions (Beck, 2002). Lower levels of depression at follow-up might be related to the better perceptions of mothers in areas of family life. It is not however apparent why tackling feelings of depression would not have resulted in better perceptions of family functioning, an area where the intervention had no impact. Additionally, the results of study four suggest that mothers who took part in the FIT-DSD intervention did not report high levels of depression. The depression scores of just over 61% of mothers feel in the normal range. Although tackling levels of depression offers a plausible hypothesis

for the success of the intervention, this seems unlikely to solely account for the results obtained. For any conclusions to be drawn, it will nonetheless be necessary for future studies to use techniques such as structural equation modeling to delineate the precise path of effect. It will also be useful to extend qualitative study of why people believe that tackling the habit web may result in changes such as those described in studies four and five. The results of studies four and five provide evidence that expanding behaviours and disrupting habits have wide ranging benefits for mothers. What is needed is understanding of why the expansion of behaviour and disruption of habits is related to benefits such as lower levels of parenting stress? Is it that simply making people less dependent on habits creates opportunity for self-generated change? Does the FIT-DSD intervention facilitate the development of cognitive and or behavioural resources for coping? What other correlates are there of improved scores on FIT variables? Can the study of these correlates tell us something about what makes the FIT-DSD intervention successful? Does tackling the habit web help with beneficial change by dealing with underlying psychological issues? These are the questions that need to be addressed to highlight why the benefits were seen in the FIT-DSD intervention group, and to specify the processes by which the benefits were achieved.

# 7.4. What does the research contribute to understanding family functioning in the context of Autistic Spectrum Conditions?

This thesis, in exploring the role of FIT Science in perceptions of family functioning, has advanced knowledge of functioning in the context of ASCs in three ways. First, the results of study three suggest that stress in mothers of children with ASCs is not solely attributed to characteristics of the child. Whilst there are undoubtedly challenges associated with raising a child with an ASC, characteristics of parents themselves contribute to resilience. Research has tended to ignore the characteristics of parents that make them resourceful and generally focused on the role of coping strategies to understand variations in adjustment. The study of FIT variables offers a route to understanding why some people use better coping strategies and why families see such varied emotional responses to the birth of a

member with a disability. The thesis has therefore pointed to directions for future research into understanding the person based correlates of successful adjustment.

Secondly, the results of study four have some useful insights for those involved with delivering services for families of children with ASCs. Study four showed that without any intervention, mothers are unlikely to report spontaneous improvement in their perceptions of their problems. The results from the control group found that over the intervention period, the problems mothers reported stayed the same. These findings are consistent with those of other studies in which control groups have been employed (e.g. Chadwick et al, 2001; Drew et al, 2002). The implications of these findings are that families cannot be left to deal with their own problems. Families with a member affected by an ASC experience unique challenges and most units are likely to need support in dealing with the constraints they encounter. This has implications for service providers when thinking about how to develop services that do not limit the support available to families in need e.g. making support accessible in terms of location, cost, relevance etc.

Finally, the findings also suggest that mothers of children with ASCs may see benefits from different types of interventions. The results of several recent studies support the effectiveness of skills training for some parents (e.g. Baharav & Reiser, 2010; Patterson, 2010). As an alternative, studies four and five nominate interventions focusing on expanding general behaviours and disrupting habits. It would of course be useful to directly compare the benefits of the FIT-DSD intervention with a skills training intervention. This would help explore whether the FIT-DSD intervention is indeed an 'alternative' approach, or a more effective approach to intervening with mothers. It is also possible that because of the focus of the intervention on tackling the habit web, benefits might be enhanced by an intervention incorporating elements of the FIT-DSD intervention with skills training. By first reducing reliance on constraining habits, parents may find it easier to implement learning through skills training. There may also be variations in the 'attractiveness' of different types of interventions. In study five, some mothers

commented on how the simple nature of the intervention lead them to initially believe that it may not help with the stressors they encounter. Parents may be more inclined to opt into an intervention in which they believe they will be taught skills, rather than be asked to focus on changing their own ways of thinking and behaving. This is not to say that skills training is more effective, although it may be 'packaged' in a way that is more appealing to parents. Future studies exploring both why the FIT-DSD intervention is effective, and comparing effectiveness with other intervention types are recommended. Furthermore, there may be value in exploring how parents make decisions about which types of support to make use of. The latter will advance knowledge of what parents expect to get out of an intervention and motivations to engage. Understanding of parent beliefs and expectations from interventions will not only benefit the development of the FIT-DSD intervention, but also traditional skills training programmes.

## 7.5. Final Thoughts

The aim of this thesis was to advance knowledge of the factors that determine why some people have a positive experience of the family, whilst others do not. Using FIT Science as a guiding framework, the thesis has shown that characteristics of the person influence perceptions across domains. This includes variations in how people perceive their family functioning, self-reported levels of depression and anxiety, and parental stress. The thesis has shown that whilst environmental and contextual factors are useful to consider, there are limitations in taking a narrow view in studying experiences of the family. Knowledge of the independent contribution of person based and environmental variables is needed to fully understand how people invent their own reality. The thesis has also shown that FIT Science offers a fruitful framework to enhance resilience to the environment and stress, and to build a more positive view of family life. Future research must draw on FIT Science to further explore the human correlates of scoring high on the Constancies and in Behavioural Flexibility. More importantly, research seeking to explore the use of FIT Science as a vehicle for family change is recommended. This

may help promote better physical and psychological health for individuals struggling with environmental and self-generated constraints.

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