An exploration of mothers' relationships with their young, non-verbal children with an autism spectrum disorder:
A case study approach

By

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Student Declaration

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution.

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ABSTRACT

There is currently considerable knowledge relating to the relationship between a mother and her child. This relationship is based upon the proposition that both mother and child are innately programmed to be sociable and the child is pre-programmed to respond to social situations and therefore elicit caregiving. Equally, adults are programmed to respond to their children. However, many parents of young children with autism have suggested that little prepares them for the limited responsiveness that many of their children exhibit.

This qualitative study, using six case studies, focused upon the reciprocal nature of the mother-child relationship in young children with autism who were also non-verbal, and sought to explore any factors which influenced the relationship experienced by the mother with her child. To date no published study has explored this relationship.

This study is based upon a naturalistic paradigm and comprised six in-depth case studies using mixed methods of data collection. Each case study includes a mother and her young child diagnosed with autism who is non-verbal. Data collection methods included a semi-structured interview, observation of mother-child interaction and the Parenting Stress Index (PSI) questionnaire which is commonly used in clinical practice. The qualitative data were coded and themes were generated. The numerical data were analysed resulting in descriptive statistics. Each case study was initially analysed separately, which was followed by cross-case analysis. The qualitative and quantitative data were integrated using a conceptually clustered matrix, which was followed by the development of an association network which displays relationships amongst the variables,

and has an associated narrative text describing the meaning of the connections between the variables.

Findings suggest that these mothers experienced difficulties in forming and maintaining a connection or an attachment with their children and deemed the interactions within the relationship to be very one-sided. This resulted in the mothers feeling rejected and unloved by their children and therefore they often did not reciprocate love for their children. Five of the mothers and children included in this study received autism-specific interventions and support. This resulted in an improvement in their children's communication and interaction, together with an increase in the mothers' understanding of autism and of their children. Conversely this resulted in an increase in the mothers' ability to be responsive and synchronise their behaviours with their children's, and in an increase in maternal confidence which culminated in a possible strengthening of the mother-child relationship.

Changes to the strategic and operational practice of professionals working with these dyads are proposed which include specific objectives for professionals comprising workshops, further research and undergraduate training to raise awareness and alter practice.

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ACKNOWLEDGEMENTS

ABBREVIATIONS

ASD: Autism Spectrum Disorder

CDC: Child Development Centre

HV: Health visitor

MPOC: Measure of Process of Care

MRO: Mutually Responsive Orientation

NHS: National Health Service

NVivo: Software package designed to assist in the analysis of qualitative data

PCT: Primary care trust

PECS: Picture Exchange Communication System

PSI: Parenting Stress Index

R & D: Research and Development

SLT: Speech and Language Therapist

CHAPTER ONE

INTRODUCTION

This thesis presents the findings of an exploration of mothers' relationships with their young non-verbal children with autism, using six in-depth case studies. This chapter offers an overview of the thesis and its structure.

A multiple case study design was used to explore these mothers' relationships with their children, using a naturalistic paradigm (Miller & Fredericks, 2002) as the main underpinning approach. A range of methods of data collection was used to allow insights from different perspectives to support my interpretations in order to give strength, depth and credibility to the findings. The findings from the mixed methods of data generation were integrated to provide multiple sources of converging evidence to enable an in-depth exploration of this phenomenon.

1.1 Justification for the study

During assessment for an autism spectrum disorder in young children, and post-diagnosis, the emphasis of interventions is mainly focused upon the child to aid communication and interaction. The mothers of these young children with autism are often expected to carry out therapy and teaching-type tasks with their children (Shields, 2001; Green, Charman, McConachie, Aldred, Slonims, Howlin, Le Couteur, Leadbitter, Hudry & Byford, 2010) until they enter formal education during the year of their fifth birthday. The difficulties experienced by children with autism in communication, reciprocal social interaction and

sometimes rigidity may cause great distress to the mother, and mothers often describe being unprepared for the limited responses shown by their children. Little appears to be understood about the impact upon the mother-child relationship of having a child who does not speak and who has considerable difficulties with communication, joint attention and interaction.

When working with families who have a young non-verbal child with autism it is imperative that there is a common understanding of this relationship and how this may influence the way in which the mother engages with professionals and interventions. The difficulties in child behaviours, such as communication, affect and responsiveness, have been found to be significantly related to maternal stress (Tomanik, Harris & Hawkins, 2004; Duarte, Bordin, Yazigi & Mooney, 2005). Theoretical models have been proposed suggesting that parental stress may influence parenting behaviours, which, in turn, may impact upon the child (Deater-Deckard, 1998; Hastings, 2002). The Department of Health: Healthy Child Programme (D.H., 2009) suggests that attachment and positive parenting in the first years of life are essential in determining future outcomes for children. It is therefore essential to understand the concept of how the mother-child relationship is constructed and whether and how certain features of child behaviour may affect this relationship development. The Department of Health: National Service Framework: Every Child Matters (2004) stated that children and young people become partners in their care with their parents, and that their needs must drive the care. This was supplemented by the Autism Exemplar (D.H., 2004) which was developed due to the large numbers of children and families affected by this significant cause of distress, and the need to provide early identification, diagnosis and intervention. The publication of The

Healthy Child Programme: pregnancy and first five years of life (2009) offers best practice guidance for practitioners in the field of early years and states that:

- Support be given to mothers and fathers to provide sensitive and attuned parenting, in particular during the first months and years of life.

- The importance of attachment and positive parenting in the first years of life is stressed in determining future outcomes for children.

To date there have been no in-depth studies carried out to explore the relationship that mothers develop with their young, non-verbal children with autism. This study therefore aims to explore this relationship and make recommendations for clinical practice.

1.2 Researcher's relevant experience

Unlike positivist studies where the researcher remains almost anonymous within the study, the role of the researcher in qualitative research is quite different and is dependent upon the relationship and the interaction that develops between the researcher and the participant (Perry, Thurston & Green, 2004b).

I embarked upon this study having had extensive personal and professional experience of autism, and was acutely aware that the focus of assessment, diagnosis and interventions is upon the child and often neglects the emotional turmoil being experienced by the mothers of these children.

Professionally I have worked as a specialist speech and language therapist in the field of autism for many years. My role for the past 11 years has been to coordinate a multidisciplinary team for the assessment and diagnosis of pre-school children with autism. This team also consists of a specialist educational psychologist, clinical psychologist, consultant community paediatrician, specialist nurse and a pre-school teacher, all of whom have extensive knowledge and experience in autism.

On a personal level I have an adult son with autism and severe learning difficulties who remains non-verbal.

During one of my visits (as a speech and language therapist) to a nursery the teacher explained that they had a young child with Down's syndrome in the nursery as well as a child with autism. She explained that the child with Down's syndrome was one of the most popular children in the nursery, because although this child was non-verbal she used every modality to engage and interact with the other children. The other children responded to this child in a very positive, reciprocal way. On the other hand she explained that the child with autism, who was also non-verbal, made no attempt to engage with or interact with the other children and therefore the other children made no attempt to interact with him. It was at this point that I wondered about the plight of the mothers of these children who also often feel rejected by their children.

1.3 Aim and objectives of the study

The initial aim and objectives, which were devised at the very beginning of the study, sought to examine the attitudes of mothers towards their young children

with autism and the effects of various interventions upon their attitudes, utilising a qualitative case study methodology. The initial aim and objectives of the study were defined as:

To examine the reported attitudes and observed behaviours of mothers with young children who have undergone a multidisciplinary assessment for an autism spectrum disorder.

Objectives:

1. To compare mothers' attitudes towards their young children following two different assessment pathways:

- Following multidisciplinary assessment where the child is introduced to and is using the Picture Exchange Communication System throughout a 17 week assessment.
- Following multidisciplinary assessment where the child has had no communication therapy throughout a two week assessment.

2. To explore whether the Picture Exchange Communication System (PECS) or EarlyBird parent training had an effect on the mothers' attitude to their children and subsequently their interaction with their children.

Data collection commenced with a pilot study which was undertaken to test out and refine the methods and to explore the emergent findings. The pilot study involved a full case study of one mother-child dyad and included all methods of data collection (interview, observation and questionnaire). Following the pilot study and analysis of the data it became apparent that there were three areas of difficulty with the original aim and objectives of the study. First, exploring the

mother's relationship with her child appeared to be more appropriate than exploring attitude because of the reciprocal nature of the interaction. The study of attitude, which is defined as 'a way of thinking about a person, object or event' (Oskamp & Schultz, 1991), involves the investigation of the mother's feelings about her child, but is a one-way dynamic or process which does not necessarily involve the exploration of how the child influences her attitude; whereas the themes that emerged from the pilot study reflected the reciprocal influences between the mother and her child. Secondly, it would have been difficult to compare the two groups of mother-child dyads using a qualitative design, and rather than change the study to a quantitative design where an in-depth exploration of the relationship would not have been possible, it was decided to change the aim to an exploratory one rather than comparative. The third difficulty was examining the effects of interventions using a qualitative design.

It was therefore decided that the original aim and objectives of the study appeared to be more suited to a quantitative design in which effects could be measured and comparisons made between two different groups. It was at this stage that the focus of this research was changed to a more qualitative design to enable in-depth explorations of the mother-child relationship and any factors which influenced this relationship. The aim and objectives were therefore revised as follows:

To explore the reported relationship and observed behaviours of mothers with their young, non-verbal children who had undergone a multidisciplinary assessment for autism spectrum disorder and any factors which may have influenced this relationship.

Objectives:

1. To explore the mother-child relationship in five mother-child dyads who received a multidisciplinary assessment where the child was using PECS, and the mother received an autism-specific training course following diagnosis.

2. To explore the mother-child relationship in one extreme or unusual case* where the child did not use PECS and the mother did not receive any autism-specific parent training.

*The one case which was unlike the other cases was not chosen as a comparison but was chosen as an unusual case (Miles & Huberman, 1994). Miles and Huberman (1994) argue that the purpose of choosing an unusual case is not to set out to compare the relationships reported by two separate groups, but to challenge the findings from the representative or typical cases.

1.4 Organisation of the thesis

This section gives an overview of the thesis:

Chapter two provides an introduction to the literature and discusses the search strategies used to discover appropriate literature for this study.

Chapter three offers an overview of the aetiology of autism, its assessment and diagnosis, the epidemiology and incidence and the interventions used by five out of the six cases.

Chapter four introduces an interpretation of the existing research related to relationship theories and includes a review of object relations theory, social

exchange theory, equity theory, attachment theory and a diverse theoretical approach proposed by Hinde (1979). The role of the mother within the relationship is briefly introduced.

Chapter five includes an in-depth review of the key literature which was believed to be relevant to this mother-child relationship. Following extensive research, using a variety of search terms and exploring a variety of different professional backgrounds, no studies were found which explored this particular relationship. Several studies however identified salient individual factors which were felt to be core components of this relationship such as stress, attachment theory, maternal responsivity etc. In this chapter an introduction to each core component is presented, followed by a critique of the methodology, validity and reliability of the studies. This is followed by an overview of five studies of mother-child relationship in adolescents and adults with autism, and finally the concept of loss and grief is discussed.

Chapter six gives an in-depth account of the philosophical paradigm, which places the research within an ontological position, the case study methodology, the various methods of data collection used and how the data was integrated. This chapter also sets the scene for the study and includes details of the participants and recruitment methods, and the diagnostic pathway utilised within the study area in Central Lancashire. The procedure for the analysis is described, followed by a discussion about the methods used to establish rigour and the ethical considerations.

Chapter seven presents the pilot study which was carried out as a precursor to the full study. As well as presenting the results of the pilot study this chapter

discusses the reflections and refinements made before the main study commenced, and offers justification for the changes.

Chapter eight presents the results from each individual case study including a short cameo and demographic information, a timeline of assessments and the diagnosis, a conceptually clustered matrix and an association network (Miles & Huberman, 1994) and a narrative of the findings.

Chapter nine presents an introduction to phase two of the analysis plan. It describes the development of the conceptual framework based on the theoretical framework proposed by Hinde (1995) which was used to explore and understand the relationship at a deeper level. Strategies proposed by Miles & Huberman (1994) for the cross-case analysis are also discussed.

Chapters ten to thirteen present the individual dimensions derived from the themes following the analysis of the different methods of data collection. Chapter ten discusses the dynamic interactions and encompasses the theme of the 'reciprocal bond', comprising the concepts of the attachment that the mother had with her child and the reciprocal nature of the joint attention and interaction within the relationship. Chapter eleven discusses the function of the mother within the dynamic interaction, including the themes 'contradiction of emotions' and 'craving normality', and focuses upon the mother's emotions and affect during and after assessment and diagnosis. Chapter twelve discusses the personal qualities of the mother and encompasses the theme 'being up to the job', relating to the concept of the responsivity or synchrony by the mother in her interaction and communication with her child. Chapter thirteen discusses the facilitators and barriers to the relationship and focuses on four themes – 'the challenge of others', 'a precarious alliance', 'a state of transformation' and 'a

journey well-travelled'. It encompasses the factors which facilitate the relationship that the mother has with her child as well as the barriers to her developing and maintaining the relationship. These include the mother's relationship with her partner and others, the process of assessment, the interventions she and her child received and finally the diagnosis.

Chapter fourteen presents the discussion and conclusions of the study and includes the theoretical implications and considerations and the contribution to knowledge.

Chapter fifteen presents the implications for clinical practice with key recommendations for practitioners and at a strategic service planning level.

Chapter sixteen proposes suggestions for future research with reflections on the process of research.

The following chapter will provide an overview of the search strategies used to carry out the literature review.

CHAPTER TWO

AN INTRODUCTION TO THE LITERATURE SEARCH STRATEGY

The previous chapter provided an outline of the thesis and included the aims and objectives of the study.

2.1 Introduction

This chapter provides an overview of the search strategies used to carry out the literature review. Chapter three offers an overview of the aetiology of autism, its assessment and diagnosis and the interventions used by the mother-child dyads. This is included in order to provide a context or to set the landscape from which to view the relationship prior to chapters four and five, which offer an in-depth review of the key literature related to the factors associated with this mother-child relationship. Chapter four explores relationship theories and chapter five discusses the core components or features of relationships relevant to this study and offers a critical review of the research undertaken in this area.

2.2 Search strategy

Several databases were used to carry out the online search for literature using the EBSCOhost online search engine. A date limitation was adopted and set the parameters for the search from 1980 to the present date. However, earlier studies which were referred to within other studies were then also included and some dated back to the substantial original papers, for example Bowlby (1958).

EndNote X4, a bibliography manager, was used in order to manage the large number of references. The databases used are listed in table (2.1).

Table (2.1) Databases used to search for literature

Database
Academic Search Complete
AMED
CINAHL
E-Journals
ERIC
Humanities International Complete
MEDLINE
PsycARTICLES
PsycINFO
SocINDEX

An extensive list of search terms was used in order to gain a broad understanding of the relationship between mothers and their autistic children, and therefore several different professional backgrounds were explored which uncovered over one thousand studies. Both qualitative and quantitative studies were included within this initial search. Any literature that was of interest was read online and literature perceived to be appropriate for this study was printed and read in full. This systematic search and review of the literature did not reveal any specific studies into this mother-child relationship. However, some wide-ranging studies were included which did focus upon other concepts related to relationships and autism. These studies were subject to a general thematic review which resulted in a catalogue of shared core components which appeared to be relevant to this study. The search terms used are detailed in table (2.2).

Table (2.2) Search terms used

Search terms used	
Autism	Relationship theory
Picture Exchange Communication System	EarlyBird
Autism spectrum disorder	Caregiving
Mother-child relationships	Bonding
Mother-child interaction	Maternal sensitivity
Mothering	Maternal rejection
Parenting	Grief
Attachment theory	Loss
Reciprocity	Mother-child synchrony
Maternal stress	Dyadic interactions
Maternal depression	Maternal competence
Interpersonal relationships	Professional support

This thematic review resulted in 496 studies of interest being identified which were reviewed in full. Although no specific studies directly relevant to my research questions were identified, there was a limited number of studies which explored mothers' relationships with their adolescent and adult children with autism which, although with a different age group, added to the understanding of this relationship.

One hundred and forty eight studies were considered to be of particular importance and were included in the full review. Due to this large number, the individual studies were not separately recorded.

In order to contextualise this study it was essential to present an overview of the aetiology of autism as well as the assessment and diagnosis of this disorder, prior to discussing the key relationship literature. As all of the cases (except the unusual case) had used the Picture Exchange Communication System, had attended the EarlyBird parent course and had received professional support an overview of these strategies is also provided.

2.3 Conclusion

This chapter has described the search strategy used to identify key literature relevant to this study. The following chapter offers an overview of the aetiology and the assessment and diagnosis of autism, the Picture Exchange Communication System, EarlyBird and professional support. This is followed by two chapters which offer an in-depth discussion with regard to the relevant key literature that was revealed during these searches. This has been divided into two separate chapters to take the reader through a distinct journey from the key theories of relationships to the core components of relationships as deemed relevant to autism and this study, and finally to the critical review of the existing literature and any gaps identified.

CHAPTER THREE

AUTISM AETIOLOGY, ASSESSMENT, DIAGNOSIS AND INTERVENTIONS

In the previous chapter I provided an overview of the search strategies adopted for this study.

3.1 Introduction

This chapter provides an overview of the aetiology of autism, assessment and diagnosis, the epidemiology and incidence. The interventions used with five out of the six cases included in this study are also discussed.

3.2 Autism

Autism is a group of neurodevelopmental disorders which are characterised by core deficits in three areas according to the International Classification of Diseases 10 (WHO, 1992), namely:

- Qualitative impairment in social interaction
- Qualitative abnormalities in communication
- Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities

The ICD-10 is used within the UK as the diagnostic criterion for the assessment and diagnosis of autism. These three areas of disability are also described as the triad of impairments and constitute an Autism Spectrum Disorder (ASD) (Wing & Gould, 1979). Although the presenting clinical picture will vary between

children, they will nevertheless all present with qualitative difficulties in each of these areas in order to receive a diagnosis. For the purpose of this study the term autism will be used throughout. Each of the three core deficits is now described in more detail.

3.2.1 Social interaction

The qualitative impairment in social interaction may include difficulties with eye to eye gaze, facial expressions and gestures in order to interact with another person. There may also be a failure to develop relationships that involve joint attention and engagement and the sharing of interests, activities and emotions, lack of socio-emotional reciprocity and a lack of spontaneity in the desire to share enjoyment with another person (Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, Swinkels, Van Daalen, Dietz, Naber, Buitelaar & Van Engeland, 2007b). Joint attention difficulties were found to be more profound in children with autism and more significant learning disabilities (Mundy, Sigman & Kasari, 1994). These difficulties may result in children with autism often appearing not to initiate or actively engage in behaviours in order to share attention, nor do they always show pleasure in an interaction, thereby appearing to be uninterested in the interaction (Sigman, Mundy, Sherman & Ungerer, 1986; Dawson, Hill, Spencer, Galpert & Watson, 1990).

3.2.2 Social communication

A qualitative impairment in communication may result in delay or lack of development in spoken language that is not compensated by the use of non-verbal communications (Lord & Paul, 1997). According to Lord and Paul (1997) approximately one third to one half of children with classic autism, as opposed to Asperger's syndrome, do not develop sufficient communicative speech to meet their everyday needs. Children who do develop language do not always use their language appropriately, and may have difficulties with initiating conversation or may use stereotypical and idiosyncratic language, and will continue to have impairment in their pragmatic use of language throughout their lives (Luyster, Kadlec, Carter & Tager-Flusberg, 2008).

3.2.3 Flexibility of thinking

The third area of the triad of impairments or diagnostic criteria is the restricted, repetitive and stereotyped patterns of behaviour, interests and activities, and can also include sensory differences (Bogdashina, 2008). Often these repetitive or sensory behaviours have a significant impact upon the individual with autism and their family and can be life-altering (Newschaffer, Croen, Daniels, Giarelli, Grether, Levy, Mandell, Miller, Pinto-Martin & Reaven, 2007; Lord & Bishop, 2010).

In addition to these three areas of impairment there may also be associated undesirable or challenging behaviours which are reported to be higher in children with autism than in children with an intellectual disability (Brereton, Tonge & Einfeld, 2006).

3.3 The assessment and diagnosis of autism

The National Autism Plan (NAPC) (Le Couteur, Baird & Mills, 2003) produced guidance for the assessment, diagnosis and planning for early intervention for pre-school and primary school age children presenting with an autism spectrum disorder. This plan suggested guidelines for the identification, assessment, interventions, resources and training all felt to be essential for the assessment and diagnosis of an ASD in young children. The NAP has been superseded by the National Institute of Clinical Excellence (NICE, 2011) guidance which proposes pathways for the recognition, referral and diagnosis of children and young people on the autism spectrum (see appendix 14, p.372 for the guidance flowchart produced by NICE (2011) for the assessment and diagnosis of autism).

3.4 Epidemiology and incidence

Autism was initially described by Kanner (1943) although several historical reports have been referred to which date back several centuries. For decades after Kanner's original paper was published in 1943, autism was generally considered to be a rare condition with a prevalence of around 2-4 per 10,000 children. Studies carried out in the late 1990s and 2000s report annual increases in the incidence of autism in pre-school children. Wing and Potter (2002) suggested that the prevalence rates were approximately 60 per 10,000 for autism and even more for the whole autistic spectrum, which was supported by Chakrabarti and Fombonne (2005). A more recent study carried out in the UK reported the incidence to be 1:100 (Baron-Cohen, Scott, Allison, Williams,

Bolton, Matthews & Brayne, 2009) and suggested reasons for these increases include changes in diagnostic criteria, development of the concept of the wider autistic spectrum, growing awareness and knowledge among parents and professionals, and the development of specialist services, as well as the possibility of a true increase in numbers.

Other developmental, behavioural, psychiatric and medical conditions commonly co-occur with autism, and recent epidemiology studies have suggested that the prevalence rate of a cognitive or learning disability co-occurring with autism is between 40% and 55% (Newschaffer et al., 2007). Behavioural challenges which may be related to the core features of autism, such as repetitive or stereotypical behaviours, may result in aggression or hyperactivity (Newschaffer et al., 2007). Sensory difficulties, although not as yet part of the diagnostic criteria, are reported to be present in 95% of people presenting with autism (Baker, Lane, Angley & Young, 2008).

Due to the core difficulties experienced by these children along with the frequently co-occurring behaviours, children with autism often present with a wide range of symptom intensity and functional disability. Studies investigating the predicting factors of functional outcome suggest that cognitive status and language acquisition are the best known predictors (Turner, Stone, Pozdol & Coonrod, 2006). A review of 24 prospective, retrospective and cross-sectional studies sought to reveal any changes in core symptoms of autism in individuals who were followed into adulthood (Seltzer, Shattuck, Abbeduto & Greenberg, 2004). Results found that the majority of adults continued to present with significant difficulties in functional ability, with the strongest predictor of outcome being IQ. Therefore children who were unable to complete an intelligence test in

the early years had poorer functional outcomes compared to children diagnosed with pervasive developmental disorders or Asperger's syndrome (Rutter & Lockyer, 1967; Walker, Thompson, Zwaigenbaum, Goldberg, Bryson, Mahoney, Strawbridge & Szatmari, 2004). Two major criticisms of these studies are firstly the length of time between assessments, some of which were carried out 10 years apart and therefore may have omitted to explore important life events experienced by these individuals with autism. Secondly there appears to have been no objective observations or measures carried out of the behaviours.

It is identified that these specific core features of autism, and co-occurring behaviours experienced and exhibited by children with autism, may have an impact upon the relationship that the mother experiences with her young child. The child factors which may have an impact include difficulties with attachment (Rutgers et al., 2007b; Koren-Karie, Oppenheim, Dolev & Yirmiya, 2009), joint attention and shared engagement (Dawson, Toth, Abbott, Osterling, Munson, Estes & Liaw, 2004; Adamson, Bakeman, Deckner & Romski, 2009) and language and communication (Landa, Holman & Garrett-Mayer, 2007). Maternal factors which may have an effect on the relationship include maternal stress and depression (Benson, 2010; Lyons, Leon, Phelps & Dunleavy, 2010; Ingersoll & Hambrick, 2011), and maternal sensitivity, responsivity and synchrony (Keen, Couzens, Muspratt & Rodger, 2010). Finally, additional factors such as the relationship the mother has with her partner (Brobst, Clopton & Hendrick, 2009), the support offered by professionals (Hill, Murray, Woodall, Parmar & Hentges, 2004; Osborne & Reed, 2008), the specific autism interventions (Bondy & Frost, 1994; Shields, 1999), parent support programmes (Cassidy, McConkey, Truesdale-Kennedy & Slevin, 2008; Keen et al., 2010), socioeconomic and family factors (Rodrigue, Morgan & Geffken, 1990) and the

manner in which the assessment is carried out and the diagnosis is given (Brogan & Knussen, 2003) may all influence the mother-child relationship.

3.5 Interventions

All of the children in this study, except the unusual case, received the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) and all of the mothers, except the unusual case, attended the National Autistic Society EarlyBird (Shields, 1999) parent training course. This next section gives a critical review of PECS and EarlyBird which is followed by a discussion regarding professional support offered to mothers.

3.5.1 The Picture Exchange Communication System

The Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) is an augmentative communication system using a pictorial system which is based upon basic behavioural principles and techniques, such as identifying reinforcers, prompting, shaping and fading of these promts to teach children to communicate spontaneously using symbols or photos. The fundamental principle of the system is to teach children functional communication and shared attention, and aims to develop the social aspect of communication and not just simply the exchange of words. The advantage of PECS over other systems is that from the outset the interaction between the child and the communication partner is intentional, with the child initiating the interaction/shared attention to request a desired item resulting in functional and meaningful communication.

PECS has been proposed as the optimal communication system for children with autism (Bondy & Frost, 1994) as it requires few complex motor movements by the child, it is not required that the communication partner is familiar with another language such as signing, and it is quick to learn in comparison to other communication systems (Bondy & Frost, 1994; Ganz & Simpson, 2004). In an initial study carried out by Bondy & Frost (2001) of 66 previously non-verbal children who were using PECS for more than one year, 44 developed spontaneous speech and 14 developed some speech. It was also claimed that these children showed a reduction in their autistic behaviours as measured by the Autism Behaviour Checklist (Krug, Arick & Almond, 1980b). None of these children, however, had standardised assessments of their cognitive functioning; therefore it is difficult to associate (Yoder & Warren, 2002) progress made in PECS without this knowledge.

A few small-scale studies have been conducted to examine the benefits of PECS (Charlop-Christy, Carpenter, Le, LeBlanc & Kellet, 2002; Ganz & Simpson, 2004). Charlop-Christy et al. (2002) found that all three children in their study showed gains in spoken language, an increase in social communication behaviours and a decrease in problem behaviours. Ganz & Simpson (2004) also supported these findings in their study on the effects of communicative requesting and speech production with three children. With such small samples, however, it is difficult to generalise these findings to the population of children with autism as a whole.

Until 2006 most of the studies involving PECS were descriptive and were mainly single case studies or non-randomised controlled trials. Several studies have compared PECS to a wide variety of different communication strategies (Adkins

& Axelrod, 2001; Tincani, 2004; Bock, Stoner, Beck, Hanley & Prochnow, 2005; Son, Sigafoos, O'Reilly & Lancioni, 2006; Yoder & Stone, 2006) or have focused their research upon the increase in spoken language, as was the focus of the original paper by Bondy & Frost (1994). However, there has been little research into the benefits of PECS as a functional communication system in which the child's initiation of joint attention has been the sole focus of the study. More recently, however, two randomised controlled studies have shown PECS to be of some benefit to non-verbal children (Yoder & Stone, 2006; Howlin, Gordon, Pasco, Wade & Charman, 2007). In a study of 36 children carried out by Yoder & Stone (2006) the use of PECS was compared with Responsive Education and Prelinguistic Milieu Teaching (PMT) which is composed of two components: one for parents and one for children. PMT is a child-led, play-based incidental teaching method designed to teach gestural, vocal, gaze use, and words as a form of clear intentional communication for turn-taking, requesting, and commenting. Although this specific technique is not used in the UK, similar strategies would be used. The findings demonstrated that in the PECS group there was a definite increase in the number of non-imitative words used and an increase in the number of spoken communications. In the study carried out by Howlin et al. (2007), in which children received seven months of intensive intervention/training in PECS, it was found that in addition to an increased use of PECS to communicate, the rate of communicative intentions also increased, but there was no increase in spoken language. In addition they found that following the cessation of treatment the intervention effects were not maintained.

The majority of studies carried out into the efficacy of clinical outcomes using PECS have been mainly non-randomised controlled trials, which some

researchers would argue do not provide a robust evidence base of the effectiveness of this form of treatment (Aldred, Green & Adams, 2004). Also as many of the studies have used very small samples it is difficult to generalise the findings. The majority of the studies have nevertheless shown that although it is not conclusive that all previously non-verbal children do develop speech following the use of PECS, they nevertheless can develop a functional communication system in which they engage and join attention with another person in order to get their message across.

In a meta-analysis of the effects of PECS on communication outcomes (frequency of exchanges, requests and initiations) and speech production (Flippin, Reszka & Watson, 2010), which included eight single subject experiments and three group studies, it was found that communication outcomes increased, whereas improved speech production was negligible. In a comparative study including 51 children between the ages of three and seven Carr & Felce (2007) investigated the communicative interactions between the children and their teachers. They reported that there were considerable increases in the initiations of communicative interactions in the children who had received the PECS training. This investigation, however, was not extended to the use of PECS with parents and therefore no evidence is available about these children's communicative interactions with their mothers.

Howlin et al. (2007) argue that it is still unclear exactly which children benefit most from PECS and the length of optimum delivery period, both of which have clinical implications.

3.5.2 EarlyBird

The National Autistic Society EarlyBird programme is a parent training course for parents of pre-school children with a diagnosis of autism. The course aims to provide parents with a greater understanding of autism, the implications of autism for their children and also strategies that parents can employ to help themselves and their children. The course is delivered over a period of approximately 12 weeks by professionals trained in the EarlyBird technique and is divided into three sections:

- Understanding the triad of impairments and how people with autism experience the world.

- Communication and autism (how children with autism communicate and interact and how parents can modify their communication and interaction to support their children).

- Identifying and understanding the behaviours often seen in children with autism, and strategies which parents can use to minimise the impact of these behaviours.

Parents attend the course together with other parents who also have children with autism, and are expected to carry out homework tasks to encourage interaction and communication with their children. These tasks are reinforced during three sessions where the parent and child are videoed interacting and communicating with each other, following which feedback is given by the professional delivering the course.

The literature search found only four studies which specifically examined the effects of the EarlyBird programme (Hardy, 1999; Shields, 2001; Engwall & Macpherson, 2003; Anderson, Birkin, Seymour & Moore, 2006). All of the

studies examined parental stress and three examined the child's autism symptomology. All studies reported that parental stress was significantly reduced, as were autistic symptoms when measured on the Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1986). These findings were consistent at a six month follow-up. The initial study, the EarlyBird efficacy study (Shields, 2001), however, was carried out by the author of the programme and therefore may have been subject to researcher bias. The most recent study which specifically examined the effects of EarlyBird was conducted in New Zealand (Anderson et al., 2006), in which a new questionnaire was developed to evaluate the effects of EarlyBird in seven areas: knowledge about autism, communication, play, behaviour management, confidence, stress and family functioning. Findings from this study indicated significant gains in all areas which were maintained at follow-up 12 months after initial training.

McConachie & Diggle (2007) carried out a systematic review of parent training courses including four studies which examined the effects of various courses for parents of pre-school children with autism. They reported positive effects with increased parental knowledge, an improvement in parental skills and performance and in one study a reduction in stress. The studies found mothers' communication strategies such as information-giving, praise, correct responses, direct responses and the total maternal utterances were significantly greater than in the control group. They also reported that there were lower levels of reported maternal depression 18 months post training in the group of mothers who had received the parent training. Improvements in children's social communication skills were also reported in one study to have significantly lower ratings in the parent training group than in the control group, as measured by the Autism Diagnostic Observation Schedule (Lord, Risi, Lambrecht, Cook,

Leventhal, DiLavore, Pickles & Rutter, 2000), indicating an improvement in autism symptomology (Aldred et al., 2004). The authors of this study suggest that the studies involved in this review did not demonstrate the effectiveness of the parental involvement in such training, as none had large enough samples to attribute the effects of the training without any doubt to parent change. Interestingly, EarlyBird studies were excluded from this review as they did not meet the inclusion criteria which involved a concurrent control or comparison group. Nevertheless the findings from these studies have important implications for this study as they enhance the understanding of the effects these training programmes have upon the mother. The focus upon family outcomes rather than simply the child's difficulties is supported by a study conducted into family counselling for parents of children with intellectual disability (Davis & Rushton, 1991).

Although these few studies demonstrated positive parental and child outcomes, what is not clear is the effect, if any, of these outcomes upon the mother-child relationship.

3.5.3 Professional support

The support that professionals offer to families with a disability has the potential to enhance or to impede the child and family outcome (Dempsey & Keen, 2008). This is particularly the case in families with a child with autism where the evidence suggests that these families are under considerable stress due to the nature of the disorder (Ingersoll & Hambrick, 2011), and that stress can have an impact upon the parents' ability to engage with their children (Konstantareas,

Homatidis & Plowright, 1992). It is also evident that the communication parents have with the professionals involved in the assessment, diagnosis and treatment can have an impact upon the levels of stress experienced by these parents (Goin-Kochel, Mackintosh & Myers, 2006). Osborne et al. (2007) suggest that failure by professionals to involve parents in interventions may exacerbate their levels of stress.

Unfortunately there is a dearth of literature relating to the positive or negative effects of professional support upon the relationship of the mother with her young autistic child. However, given that studies have suggested that professionals can have an impact upon family outcomes, it could be proposed that this may have an impact (Goin-Kochel et al., 2006; Dempsey & Keen, 2008; Osborne & Reed, 2008).

One study, which sought to understand parents' perceptions of the diagnostic process and the support received, reported that 36% of parents perceived that they had not received any help or support (Osborne & Reed, 2008). This study was based upon parental report during focus groups; however, there were no independent reports of what support had actually been offered to these parents. It is important to distinguish between actual and perceived support as these parents may have been experiencing a great deal of stress, and therefore may have had difficulty in recognising what support was being offered. An empirical study which examined parental satisfaction during the disclosure of a diagnosis of autism (Brogan & Knussen, 2003) found that parents who reported a higher level of satisfaction were more positive about the way in which the professionals were involved.

Numerous studies have proposed the use of a family systems theory (Bowen, 1978) which underpins a model of service delivery, used mainly in Australia, for parents of children with disability and recognises the needs of all family members and not just the member of family with a disability (Murray, 2000; Dempsey & Keen, 2008). Although this theory does not specifically examine the effects of professional support upon the mother-child relationship, it does nevertheless acknowledge the effects of and importance of professional support on parental wellbeing. Although there is no equivalent terminology used within the UK the principles of this theory are practised within some localities, and in particular within NHS Central Lancashire's diagnostic pathway. Therefore these studies add to the understanding of the effects professionals may have on the mother-child relationship. Central to family systems theory is the recognised relationship between the parent and the professional in which decision making, mutually agreed goals, mutual respect, trust and honesty are practised.

Dempsey and Keen (2008) carried out a systematic literature review of empirical studies which were identified through searches using PsycINFO and ERIC databases. Thirty-five studies which included conceptual or practical evidence of using family-centered principles since 1987 were included. These studies sought to examine the relationship between the actions professionals undertake with families (help-giving) and what results from these actions (outcome). Parent and child outcomes included: parental stress and well-being, measures of control, parenting competence, child development, child behaviour problems and level of disability. The moderating variables included characteristics of the children, families and staff, satisfaction with support and parental control. This review claimed that help-giving resulted in an increase in parent empowerment, locus of control and satisfaction, which resulted in

improved child development and parental satisfaction with the child's development. What is not evident from these studies, however, is how these improvements in locus of control, empowerment etc. affect the relationship that the mother has with her disabled child. The findings from these studies were often inconsistent, with important variables such as child development receiving little attention, and the failure to demonstrate any significant association between help-giving practices and parenting competence. It could be argued therefore that it is difficult to draw any firm conclusion regarding the effects that the 'help-giving' practices had upon the outcomes for the families involved.

3.6 Conclusion

This chapter has offered an overview of autism, the assessment and diagnosis and the interventions offered to these dyads. The next chapter will discuss relationship theories.

CHAPTER FOUR

RELATIONSHIP THEORIES

The previous chapter provided an overview of the aetiology of autism and briefly discussed the assessment and diagnosis.

4.1 Introduction

The following two chapters offer a review of the key literature related to the factors associated with the mother's relationship. This chapter presents an interpretation of the existing research of relationship theories which contextualises the research undertaken in this area, prior to discussing the core features of the relationship discussed in chapter five.

4.2 Relationship theories

The literature search revealed several different theories of interpersonal relationships which could be related to the mother and her child. An overview of these theories is presented and the role of the mother is discussed. Object relations theory (Fairbairn, 1952) is a psychoanalytical theory of relationships between people, in particular between the mother and her child. A basic assumption is that humans are driven to form relationships with others and that failure to form successful early relationships leads to problems in later life. Social exchange theory (Befu, 1977) is a social psychological theory and proposes that social behaviour is the result of negotiated exchanges between

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two people, and that relationships are based upon exchanges which maximise benefits and minimise costs. According to this theory, people decide upon the potential benefits and risks of the social relationship, and when the risks outweigh the rewards the relationship is terminated or abandoned. Equity theory (Adams, 1965) focuses on determining whether the distribution of resources is fair to both partners within the relationship. Object relations theory, social exchange theory and equity theory have all been criticised (Huseman, Hatfield & Miles, 1987; Miller, 2002) for their simplicity and failure to embrace the dynamic nature of relationships. As this study aimed to elicit a holistic interpretation of the mother-child relationship these theoretical frameworks were not deemed to be suitable for further consideration.

4.3 Attachment theory (Bowlby, 1958; Ainsworth, Blehar, Waters & Wall, 1978)

The concept of attachment was originally defined by Bowlby (1958) and is defined as a specific tie or affection that one person forms with another and, once formed, patterns of attachment behaviour endure across space and time (Bowlby, 1958; Ainsworth et al., 1978). In developing his theory of attachment Bowlby (1958) studied the works of Dollard & Miller (1950), who proposed a dominant behavioural theory and argued that the child became attached to the mother simply because she fed the infant. Bowlby (1958) disagreed with this theory and proposed that attachment was derived from an evolutionary concept (Harlow, 1958) where the child sought safety and security in order to enhance its chance of survival. The central theme of Bowlby's attachment theory is the mother's (or mother figure) availability and responsiveness to her infant's needs

which in turn establishes a sense of security in her child. The infant understands that the caregiver is dependable, which creates a secure base for the child to then explore the world. The understanding of attachment theory was further progressed by Ainsworth et al. (1978) who proposed three styles of attachment: secure attachment: securely attached children demonstrate distress when the mother leaves the room. They are avoidant of strangers when alone but friendly when the mother is present and are positive and happy when the mother returns. Ambivalent-insecure attachment: ambivalent-insecurely attached children show signs of intense distress when the mother leaves the room. The infant avoids the stranger and shows fear. On reunion the child approaches the mother but may push her away. Avoidant-insecure: avoidant-insecurely attached infants show no sign of distress when the mother leaves and are happy in the presence of strangers. The infant shows little interest when the mother returns. These styles of attachment are assessed using the Strange Situation Procedure (described below).

When exploring the concept of the mother-child relationship many authors anecdotally describe this relationship through the concept of attachment theory. However attachment theory relates to the bond or tie between an infant and an attachment figure, which in children is often the mother, and relates to the child's functions to receive protection (Ainsworth et al., 1978) and not the mother's attachment to her child. A limited number of studies have explored attachment theory in adults (Slade, 1999; George & West, 2012) but these studies have explored adults' romantic attachment to one another and not attachment of an adult to a child. The term used to describe the attachment equivalent of the mother to the child is the 'caregiving bond' (Bowlby, 1983; Prior & Glaser, 2006) or, as Ainsworth et al. (1978) suggested, 'maternal

sensitivity', which is thought to be synonymous with the term attachment and is used to describe the parent's innate desire to provide protection for the survival of the child. The caregiving bond or maternal sensitivity is described as a biological behaviour with specific behaviours that are displayed by the parent and are dependent upon the parent's own experiences during childhood and adolescence (Bowlby, 1983).

Prior and Glaser (2006) argue that attachment between two adults is often reciprocal but the relationship or attachment between the child and parent may not be. The attachment relationship between the mother and her child is seen as the outcome of the child's experiences of interactions with the mother over the first year of life (Ainsworth et al., 1978), and the child's behaviour reflects his or her anticipation of the reaction of the parent to his or her seeking comfort and, as Rutgers et al. (2007b) suggest, influences the child's strategies for regulating his or her emotions and stress.

The majority of attachment studies have used the Strange Situation Procedure (SSP) (Ainsworth et al., 1978) to measure attachment of the child to the caregiver. This involves coding behaviours during a momentary separation and reunion of the caregiver and child. The child is scored as securely attached, ambivalent-insecurely attached or having a disordered attachment (avoidant attachment), depending upon the behaviours displayed during the SSP (Ainsworth et al., 1978). There are however criticisms of this procedure and its measurements. Firstly Field (1996) argues that a broader understanding would be gained from observing the mother and child during naturalistic interactions as the SSP was developed to be carried out in a laboratory setting. This method also only measures separations and reunions, and one could question whether

this truly reflects a child's attachment, particularly in the light of children with autism who may find a strange environment challenging. A further criticism has been made by Harris and Parker (1998), who argue that children learn from their social groups and other attachment figures rather than solely the main carer. Children with autism can occasionally develop an intense, obsessional attachment to one or other caregiver, sometimes to the detriment of the other. Therefore the robustness of this assessment in its use with children who have autism has to be questioned if the caregiver that they are not intensely attached to is not present during the assessment.

The 'caregiving bond' or 'maternal sensitivity' and child attachment systems are thought to work in harmony with both parent and child aiming to be near each other (Bowlby, 1983), and the development of the relationship between a mother and her child is based upon the proposition that both she and her child are innately programmed to be sociably responsive to one another (Bowlby, 1983). Studies involving typically developing infants demonstrate the importance of the process of attachment in forming a reciprocal mother–child relationship (Ainsworth et al., 1978). Initially babies engage in behaviours especially effective in eliciting parenting care which invoke parent attachment. During the early weeks of the child's life the newborn infant displays simple repetitive movements which include smiling and crying; these behaviours are modified in order to elicit an affective response from the mother. Individual differences in babies' behaviours may be perceived by the mother as involving differences in dimensions such as 'cuddliness' and 'lovingness' which are thought to be relevant to the development of the mother-child relationship (Schaefer, 1977). Subsequently the infant develops intentionality and emotional expressivity which is directed towards the mother. These infant behaviours such

as smiling, emotional sensitivity and reciprocity form the basis of important relationships and attachments between the mother and her child and are reinforced by these positive experiences (Bowlby, 1983).

In light of these theories it could be argued that children are pre-programmed to respond to social situations and therefore to elicit 'caregiving', and that adults are pre-programmed to respond to their child and therefore provide 'caregiving'. These innate social behaviours, described as interactional synchrony, lead to the formation of relationships and attachments which are reciprocal, with the mother-child interactions being compared to a dance as each participant follows and responds to the other's moves (Brazelton, Tronick, Adamson, Als & Wise, 1975).

As attachment theory (Bowlby, 1958; Ainsworth et al., 1978; Bowlby, 1980) has received the most significant attention over the years as a relationship theory it has included studies of parents with children with autism (Rutgers, Bakermans-Kranenburg, Van Ijzendoorn & Berckelaer-Onnes, 2004; Rutgers, Van Ijzendoorn, Bakermans-Kranenburg & Swinkels, 2007a; Rutgers et al., 2007b; Koren-Karie et al., 2009; Seskin, Feliciano, Tippy, Yedloutschnig, Sossin & Yasik, 2010a). The construct of attachment theory, however, within the broad theoretical framework of relationships refers only to the mother's and child's behaviours in order to achieve and give protection, security and closeness (Ainsworth et al., 1978), and does not necessarily give a holistic overview of every aspect of the relationship. Although attachment has been the most common theory used to describe the parent-child relationship and is of vital importance in aiding the understanding of one aspect of the relationship, Bowlby (1983) also proposed other constructs which emphasise the

involvement of other dynamics such as feeding, playing and learning. Bowlby (1980) argued however that attachment-caregiving is given top priority within the theory of relationships. Other authors have suggested alternative dynamics such as affection (George & Solomon, 1999), warmth, emotional availability and nurturance (Zeanah Jr & Boris, 2000), and the shaping of social experiences and conversational interchanges (Rutter & O'Connor, 1999) from which to view the relationship. Very little else however has been written with regard to these other dynamics that are proposed.

4.4 A diverse theoretical approach

Hinde (1995) proposes a diverse theoretical approach which integrates sociology, psychology, psychoanalysis, anthropology and biology in order to best describe an interpersonal relationship. He argues that the division of the phenomena into the theories already discussed does not allow for a holistic understanding of the relationship. He suggests that the nature of any interpersonal relationship is extremely complex at many different levels, and although it is not possible to analyse every single thought, behaviour or interaction he does suggest that it is possible to observe and record certain indicators within the relationship in order to describe some of the complexities:

> *'A relationship implies first some sort of intermittent interaction between two people, involving interchanges over an extended period of time. The interchanges have some degree of mutuality in the sense that the behaviour of each takes an account of the behaviour of the other'.* (p. 37)

The relationship between the mother and her child is conceptualised by Hinde (1979) as the connecting and binding qualities of the mother and her child in relation to each other. This involves a series of interactions which span over

time with each interaction being affected by behaviours that have happened in the past and anticipations about what may happen in the future. Therefore, in the case of the mother and her child she may reflect on previous behaviours that have happened during an interaction in the past, such as a perceived rejection by her child, and this experience subsequently influences her conceptualisations of what may happen within future interactions. Hinde (1995) also argues that the precise dividing line between an interaction and a relationship is impossible to describe, but that an interaction is limited in time whereas a relationship evolves over a longer time period. He suggests that interactions can be classified according to the extent to which the response of the mother or the response of the child is determined by the preceding behaviour of the other participant. Hinde (1995) also argues that the quality of the interaction is as important as the interaction itself. For example, a mother may say something to her child but *how* it is said during the exchange may differ from its content. Therefore he proposes that the effect of one interaction on subsequent interactions depends not only on what actually happens during the interaction, but also on what each partner within that interaction thinks about the experience during the interaction. Discrepancies may therefore arise between how the mother describes her relationship with her child and how she actually behaves or interacts with her child. What she thinks about the relationship may be more important to her than the interactions that actually occur between her and her child, particularly in the case of a child with autism who may experience difficulties with interaction. (For a further discussion of the application of Hinde's theory see chapter 4.4 p.37)

4.5 The role of the mother in the relationship

Bringing up a young child with autism can be a very demanding task and presents significant challenges for parents of these children. This lifelong disability can present with unique behavioural features which are often challenging for parents compared with other developmental disorders (Beauchesne & Kelley, 2004). The severity of the disability, the specific diagnosis and the age at which the child is diagnosed are all factors which have been found to influence how families cope with children who have a developmental disability (Perry, Harris & Minnes, 2004a). Within families the mother often assumes the primary caregiver role (Konstantareas et al., 1992), and studies of children with autism and other developmental disabilities have shown that mothers as opposed to fathers take on the primary caregiver role (Bristol, Gallagher & Schopler, 1988); therefore the majority of studies carried out with parents of children with autism have focused upon the experiences of mothers.

From an extensive review of the literature it appears that there is only a limited number of studies exploring the lived experience of parenting a child with autism. A qualitative study carried out by Cashin (2004) explored parents' experiences of parenting a child with autism using hermeneutic phenomenology. Cashin identified that parents experienced less social contact and less spontaneity in their lives. Parents also expressed the concept of 'less self'. He argued that autism dominated the parent-child interaction and relationship, and as spontaneity leaves the parent-child relationship it also leaves 'the self'. He suggested that autism not only affected the current self but also the future self. A later study, also using hermeneutic phenomenology, also

explored parents' lived experiences of parenting a child with autism (Woodgate, Ateah & Secco, 2008). This study revealed that these parents experienced not only difficulties in their role as parents, but also a sense of isolation.

Both of these studies involved small numbers of families and the Woodgate et al. (2008) study was carried out in Canada, and therefore may not be transferable to this population in the UK; however, both studies highlight areas of difficulty experienced by parents of children with autism.

4.6 Conclusion

This chapter has offered an interpretation of the two most relevant theories of interpersonal relationships and has also given justification for why other relationship theories were inappropriate. The following chapter will present and explore previous research which has identified key factors associated with the mother-child relationship.

CHAPTER FIVE

THE KEY FACTORS INFLUENCING MOTHER-CHILD RELATIONSHIPS

The previous chapter provided an interpretation of the theories of interpersonal relationships. This included an in-depth discussion regarding attachment theory and an introduction to the diverse theoretical approach.

5.1 Introduction

It is the intention of this chapter to present an in-depth review of the key literature relating to mothers' relationships with their young children with autism. As identified, the exploration of the literature revealed no studies which specifically explored this relationship. However, this review discusses salient maternal and child factors which were identified in the literature which are understood to be core features of this relationship. The literature was reviewed, synthesised and grouped into core maternal and child components of the mother-child relationship. In the following sections an introduction to each component is described followed by the findings from various related studies. A critique of the methodology, validity and reliability is offered at the end of each section. This is followed by a review of the dyadic interactions between mothers and their children and subsequently an overview of five quantitative studies which investigated the relationship of mothers with their adolescent and adult children with autism. Finally, an analysis and critique of the literature relating to loss and grief is presented. This chapter concludes with a summary of the literature.

5.2 Core components of the relationship

The mother-child relationship consists of various maternal and child components which influence and have implications for the development and quality of the attachment relationship. The importance of this relationship is not only vital from the mother's point of view but also from that of the child, and as Anderson, Riesch, Pridham, Lutz & Becker (2010) point out:

> *'The importance of the parent-child relationship to optimal child outcomes has been established across cultures and socioeconomic levels'* (p.111)

This next section will review the literature relating to maternal and child factors and a critique of the literature will be offered.

5.3 Maternal factors

The maternal factors which were identified as being salient throughout the literature included maternal sensitivity, responsivity and synchrony, maternal stress and the relationship with her partner. Each is discussed in turn.

5.3.1 Maternal sensitivity

Maternal sensitivity refers to the mother's awareness of her affect upon her child and includes her flexibility, her acceptance of her child's difficulties with interaction and, most importantly, her awareness of her child's cues (Baker & McGrath, 2011). In addition to studies which focus upon children's attachment, several empirical studies have sought to explore the resources that mothers

require in order to support their children in their attachment (Ainsworth et al., 1978; Oppenheim & Koren Karie, 2002; Koren-Karie et al., 2009; Oppenheim, Koren-Karie, Dolev & Yirmiya, 2009). Authors discuss maternal insightfulness, which is the capacity of the mother to see things from the child's point of view (Ainsworth et al., 1978), or insightfulness and resolution in which mothers who are insightful and are able to interpret their child's needs and signals, and who are also resolved in their acceptance of their child's diagnosis, are more likely to have securely attached children (Oppenheim et al., 2009).

A study of attachment and maternal sensitivity in 45 pre-school boys found that, despite their children's level of functioning, mothers of securely attached children with autism displayed more sensitivity towards their children than mothers of insecure children (Koren-Karie et al., 2009). Therefore their argument is that despite the children's significant impairment in their ability to indicate and communicate their needs, mothers nevertheless were able to adapt their behaviour to meet the needs of their children.

5.3.2 Responsivity / Synchrony

Maternal sensitivity can be distinguished from responsivity or synchrony as the latter refers to the appropriate timing of the interactions by the mother which are mutually rewarding and therefore synchronous, whereas sensitivity refers to the mother's awareness of her child's cues (Baker & McGrath, 2011). The mother responds immediately following her child's behaviours with behaviours that are closely related to those behaviours (Yoder & Warren, 1998). Therefore these complex interactions are related to the mother's competence to synchronise her

behaviours with those of her child. A secure attachment to his or her mother enables the child to develop confidence and independence and see the mother as sensitive and responsive in her interactions.

Several different terms have been used to describe and study this concept such as responsivity (Yoder & Warren, 1998), mutually responsive orientation (Aksan, Kochanska & Ortmann, 2006) and synchronicity (Siller & Sigman, 2002; Feldman, 2007); others have described it in terms of following the child's lead (Watson, 1998). All of these studies discuss the importance of the mother or caregiver's timely response to her child for the promotion of social and emotional engagement and communication. Feldman (2007) also suggests that maternal behaviour and infant personality have an influence upon the experiences of synchronicity. Furthermore, although a variety of terms are used to describe these phenomena, there is agreement that the influence of the reciprocal nature of the relationship between the mother and her child is crucial to the development of a secure relationship.

Baker & McGrath (2011) carried out an integrated review of the literature relating to mother-infant synchrony, which included 23 studies conducted since 1985 involving infants up to the age of twelve months. Infants with any disability were excluded from the review. The objectives of the review were to formulate a consensus of a working definition, characteristics and measurement of synchrony, and to review the maternal and infant outcomes related to synchrony. The definition of synchrony was agreed as:

> *'A dynamic relationship that is mutually engaging, temporally coordinated and includes an element of contingency'* (p.12)

Certain maternal characteristics were found to contribute to maternal-infant synchrony and these included maternal sensitivity, maternal responsiveness and the mother's emotional state such as stress and depression. The support given by others also contributed to the mother's ability to synchronise her behaviours with those of her infant. The temperament of the infant was found to contribute considerably to mother-infant synchrony, and mothers of infants who were irritable or who did not sleep were found to have considerable difficulties in fostering social and emotional growth in their infants. Most interesting were the findings in relation to the effect of the infant upon the mother. As mothers learnt to interpret the behaviours of their children and respond appropriately by being sensitive and responsive, this resulted in mothers developing a sense of competence in their own role. Equally, mothers who found it difficult to interpret and understand the signals given by their infants found they lacked competence and confidence and were at greater risk of developing depression and anxiety. Aksan et al. (2006) argued that a relationship must be viewed as being mutually cooperative and binding and is measured using the construct of Mutually Responsive Orientation (MRO). This construct aims to capture the interactive quality of the dyadic interaction rather than simply the individual observed behaviours, and includes four in-depth dimensions of the dyadic relationship: coordinated routines, harmonious communication, mutual cooperation and emotional ambience. Their findings indicated that dyads who had high scores for MRO demonstrated behaviours which were 'flawlessly' meshed with each other and enjoyed a back and forth communication and interaction which promoted the connection between the dyad. On the other hand, dyads that had low scores on the MRO failed to coordinate their interactions with each other resulting in a failure to read each other, ultimately leading to disconnection.

Siller & Sigman (2002) investigated the synchronous behaviours of parents and infants during play. The sample included 25 children with autism, 18 dyads with children with developmental delay and 18 typically developing children. They found that parents of children with autism synchronised their behaviours as much as the parents with children who were developmentally delayed and typically developing. They also suggested that parents who were better able to synchronise their behaviours with their children resulted in children with better joint attention and language skills at the ages of one, ten and sixteen years.

Although these studies have certain limitations in terms of methodological issues and their generalisation to the present study, the findings highlight the importance of the ability of the mother to synchronise and regulate her behaviours with those of her child. In order to respond to her child she requires confidence in her own ability to interact with her child. This however may be difficult to achieve when the child is unable to synchronise his or her behaviours with the mother. Although no children with autism were included in the Aksan et al. (2006) study they did demonstrate the importance of the relationship being mutually cooperative. The results of the Siller & Sigman (2002) study are positive, although have never been repeated, and indicate that the parents of the children with autism did synchronise their behaviours as well as parents from the other two groups. The Aksan et al. (2006) study was conducted with 102 families of typically developing children but was carried out in the USA and, unlike the Baker & McGrath (2011) study, included both the mother and the father. The Siller & Sigman (2002) study also included both parents, and the children were reported to already have some language skills and were, albeit in a limited way, able to initiate and respond to shared attention. The Baker & McGrath (2011) study only included infants under the age of 12 months and

excluded infants with any known disability. This study does, however, highlight the effects of the infant upon maternal competence and wellbeing.

5.3.3 Maternal stress and depression

There is a significant body of research which argues that bringing up a young child with autism can be a very demanding task and presents significant challenges for parents. Although the current study does not seek to explore stress in these mothers in any great depth, previous research has identified stress to be a key influence upon the mother-child relationship. The results from several empirical studies suggest that parents of children with an autism spectrum disorder experience higher levels of psychological distress or stress than parents of children with other disabilities and of typically developing children (Holroyd & McArthur, 1976; Dumas, Wolf, Fisman & Culligan, 1991; Schieve, Blumberg, Rice, Visser & Boyle, 2007; Dabrowska & Pisula, 2010), and that stress can have an impact upon the parents' ability to engage with their children (Konstantareas et al., 1992). Several studies have argued that stress appears to be particularly prevalent in mothers of children with autism since they typically assume the greatest responsibility as the primary caregiver (Wolf, Noh, Fisman & Speechley, 1989; Eisenhower, Baker & Blacher, 2005; Estes, 2009). Moreover, in studies which have explored stress in both parents of children with autism the majority have included higher numbers of mothers than fathers (Davis & Carter, 2008). However, in an exploration of stress experienced by both mothers and fathers of pre-school children, it was stated that although fathers reported high levels of stress, mothers were found to have consistently higher levels of stress and depression scores than fathers (Davis &

Carter, 2008). This would suggest that mothers appear to be more fundamentally affected by the difficulties experienced by their children.

Various factors have been examined in an effort to explain the increased stress experienced by mothers. From the literature it appears that the interactions between several sources of stressors result in an increase in stress or distress. Mouton & Tuma (1988) suggested that stress in mothers appeared to be related to both parent and child characteristics rather than to child behaviours alone. One study suggested that individual maternal variables can have an effect upon child behaviours (Crnic & Low, 2002) and vice versa, child variables can also have an effect upon the mother's behaviours (Maccoby & Martin, 1983). Theoretical models have been proposed suggesting that parent stress may influence parenting behaviours, which, in turn, may impact on the child (Deater-Deckard, 1998: Hastings, 2002).

The different sources of stress experienced by parents of children with autism identified within the literature include parental characteristics such as competence, locus of control (Mouton & Tuma, 1988), mental health and depression (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy, 2004; Montes, 2007). Child characteristics which have been attributed to parental stress include difficult behaviours (Noh, Dumas, Wolf & Fisman, 1989; Lecavalier, Leone & Wiltz, 2006; Estes, 2009), reciprocal social interaction difficulties (Davis & Carter, 2008), communication and affect (Donenberg & Baker, 1993). The relationship between all of these child behaviours has been found to be significantly related to maternal stress (Tomanik et al., 2004; Duarte et al., 2005). Resources and aggravations such as family cohesion and social

supports have also been reported to be equally as stressful (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins & Plienis, 1992).

Many of these empirical studies have suggested that a source of stress may include difficulties with communication and interaction experienced by these children; however, very few studies have examined these two variables in detail or in isolation in order to demonstrate their impact upon the mother-child relationship. Ingersoll & Hambrick (2011) found that child symptom severity had a direct effect upon parental stress and depression. This study used the Autism Behaviour Checklist (Krug, Arick & Almond, 1980a) to measure symptom severity, which explores specific behaviours associated with autism such as verbal and non-verbal communications, interactions and behaviours. A further study into the correlation of severity of childhood autism symptoms, such as receptive and expressive language, hyperactivity, mood, social withdrawal etc., with maternal stress revealed that child symptom severity was significantly and positively associated with stress (Benson, 2006). This finding was previously established by Hastings & Johnson (2001). Kasari & Sigman (1997) also identified that children who demonstrated better ability to share attention with their parents had parents who were less stressed, and Davis & Carter (2008) argued that delays/deficits in reciprocal social interaction had a significant impact on stress; however, they did not find that communication difficulties were salient predictors of stress, particularly language delay. Plant & Sanders (2007) suggested that the presence of child behaviour problems had a significant impact upon maternal stress, and to a lesser degree higher levels of stress were reported in parents of children with a more severe disability. This was supported by Phetrasuwan & Shandor Miles (2009) in a correlation study which established that the behaviours that were most salient in causing maternal

stress were the child's emotional responses, but they also suggested that difficulties with verbal communication were also a significant cause of stress.

Maternal parenting satisfaction was found to be affected by 'daily hassles', in which stress was conceptualised as being daily minor events of frustration rather than one major event (Crnic & Greenberg, 1990). In a longitudinal study carried out over two years, 141 families of typically developing children aged three years were measured for stress and parent-child interaction. The effects of stress using subjective and objective measures demonstrated the impact that cumulative stress builds over developmental periods, creating increased risk for parenting and child functioning and ultimately the parent-child relationship (Crnic, Gaze & Hoffman, 2005). Although this study did not include children with autism, it nevertheless strengthens the argument that parent-child interaction influences stress.

As can be seen from these studies, there are several different maternal and child characteristics which are related to maternal stress. Several of these studies have implied that children with more significant communication, interaction and behavioural difficulties are more likely to cause more stress to the mother. Apart from the study carried out by Crnic et al. (2005), none of these studies have sought to demonstrate the impact of this stress upon the mother-child relationship.

Certain weaknesses are apparent in several of these studies. The measurement of stress in several studies has been relatively subjective with mothers completing questionnaires reflecting their perceptions of stress in major life events. Crnic et al. (2005) suggest that it is critical to independently observe behaviours in order to avoid the potential subjectivity found in self-reported

questionnaires. Two studies failed to isolate the specific child variables (Hastings & Johnson, 2001; Benson, 2006). Krug et al. (1980a) failed to isolate the impact of any of the specific behaviours and therefore, although they suggested that the severity of child symptomology affected parental levels of stress, they were not able to relate which symptom was the cause of the stress. In the Davis & Carter (2008) study the mean age of this sample was 26.9 months and all of the parents were participating in an intensive early intervention service with a strong emphasis on language and communication skills, and therefore may have been unrealistically optimistic.

5.3.4 Relationship with partner

It has already been demonstrated that stress amongst parents of children with autism is higher than in those with children having other types of disability (Dabrowska & Pisula, 2010). There is also evidence which suggests that stress affects a couple's relationship, and parents of children with autism often find that the stress of parenting a child with autism is intensified because of the increased incidence in challenging behaviours (Brobst et al., 2009). Parents of children with a disability are more likely to experience a separation or divorce than those of children without a disability (Risdal & Singer, 2004). A comparative survey carried out in the United States examined the occurrence of divorce in 391 white, non-Hispanic parents of children with autism and a matched representative sample of parents of children with no disability. Their findings demonstrated a divorce rate of 23.5% in the parents of the children with autism compared to 13.8% of the parents of children with no disability (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010).

The quality of the relationship that the mother experiences with her partner is therefore obviously at risk when her child has autism, but what is less well understood is whether the stress experienced by these couples and the breakdown in their relationship affects the relationship that the mother has with her child.

In an empirical study Brobst et al. (2009) examined the relationship quality, parental stress and variables that had an effect on the relationship of couples who had children with autism, compared to those who did not. Twenty five families with children between the ages of two and 12 years were included and all children had a diagnosis of autism, Asperger's syndrome, or pervasive developmental disorder not otherwise specified. Six different questionnaires were used to rate each individual parent's levels of stress, social support, respect for each other, commitment towards each other, relationship, and their child's behaviour. Results indicated that parents of children with autism reported higher levels of stress and lower levels of relationship satisfaction than the parents in the comparison group. The levels of stress were greater for parents when the positive relationship characteristics such as satisfaction, social support and commitment were lower, and mothers of children who had autism and challenging behaviours reported lower levels of support, respect for their partners and commitment to their marriages from their partners.

There are certain limitations to this study, however, as there appeared to be no independent confirmation of a diagnosis of autism, Asperger's syndrome or pervasive developmental disorder in any of the children, and diagnosis was confirmed on parental report alone, as was their children's level of challenging behaviour. There also appeared to be no measures of any of the children's

cognitive or communication ability, which may have had a significant impact upon the levels of stress experienced by these parents. The majority of the parents took the questionnaires home to complete independently. It is therefore possible that the couples may have conferred during the questionnaire completion, affecting the reliability and validity of the scores. Finally, the individual scores from the mother and father, which are reported to have differed greatly in some instances, were combined in order to create a single score for each couple.

5.4 Child factors

The child factors which were identified as being salient throughout the literature included attachment in children with autism, joint attention and communication. Each is discussed in turn.

5.4.1 Attachment in children with autism

Autism is characterised by impairments in social communication and reciprocal social interaction (Sigman et al., 1986; WHO, 1992; A.P.A., 1994; Rutgers et al., 2007a). (See chapter 3.2 p.15 for a full definition of autism). Children with autism often do not initiate or actively engage in behaviours in order to share attention, nor do they always show pleasure in an interaction, appearing uninterested in the interaction (Sigman et al., 1986; Dawson et al., 1990). Furthermore, if either parent or child is unresponsive in this interaction, this may

result in an affective disturbance within the relationship (Field, Healy, Goldstein & Guthertz, 1990).

A child who elicits and responds to social interactions is more likely to form a relationship with their caregiver. Therefore if the child's attachment system is not in harmony or synchronised with the caregiver, and the child does not reliably display attachment behaviours, this will significantly impair the caregiver's attachment to and relationship with the child. This is supported by findings of a study conducted by Whitaker (2002), who states that many parents of young children with autism have suggested that little prepares them for the limited responsiveness that many of their children display, and what they strive for is a sense of connectedness that develops naturally in typically developing children.

A considerable number of empirical studies have been published in reference to attachment (chapter 4.3, p. 22) behaviours of children with autism with their caregivers (Sigman & Ungerer, 1984; Rogers & Ozonoff, 1993; Capps, Sigman & Mundy, 1994; Dissanayake & Crossley, 1996; George & Solomon, 1999; Rutgers et al., 2004; Prior & Glaser, 2006; Rutgers et al., 2007a; Van IJzendoorn, Rutgers, Bakermans Kranenburg, Swinkels, Van Daalen, Dietz, Naber, Buitelaar & Van Engeland, 2007). An initial empirical study to examine attachment in children with autism was carried out by Sigman and Ungerer (1984), in which they used a modified version of the Strange Situation Procedure (Ainsworth et al., 1978). They identified that although the group of children with autism displayed fewer attachment behaviours than the typically developing group of children, they nevertheless were found to be capable of forming attachments with their caregivers.

A qualitative and quantitative meta-analytical review (Rutgers et al., 2004) of 16 studies of attachment in children with autism sought to examine three questions:

- Do children with autism establish a secure attachment relationship with their parent in the same way as control children?
- Is the security of attachment in autism associated with cognitive development?
- Is there a relationship between attachment security and the chronological age of children with autism?

They concluded that children with more strictly defined autism, which they describe as children whose autism symptoms had a more significant impact on daily living skills, were less securely attached and showed less responsiveness in their interaction with caregivers. Children with more significant difficulties in cognitive development showed more signs of insecure attachment than comparative children, but chronological age did not affect attachment. Therefore the more severe the core symptoms of autism and cognitive impairment, the less likely the child is to display a secure attachment to the caregiver. This was confirmed by Rutgers, van Ijzendoorn, Bakermans-Kranenburg, Swinkels, van Daalen, Dietz, Naber, Buitelaar & van Engeland (2007b), who concluded that severity of autism and the child's developmental level were important moderators of attachment security.

More recent studies have examined the attachment of toddlers with autism compared to children with other developmental disorders. An investigation, carried out in the Netherlands, examined the distribution of attachment

classifications during the SSP (Ainsworth et al., 1978), in 62 pre-school children who were divided into four groups: Autism spectrum disorder, Pervasive Developmental Level not otherwise specified, Mental Retardation and Language Disorder. Findings demonstrated that the severity of the autism was associated with the level of attachment insecurity, and children who presented with more severe autism symptoms presented as being more insecure. They also found that with an increased learning disability there was an increased chance for a disorganised attachment (Naber, Swinkels, Buitelaar, Bakermans-Kranenburg, van IJzendoorn, Dietz, van Daalen & van Engeland, 2007). These findings were supported in a subsequent study, also carried out in the Netherlands, with 89 children and their parents which sought to compare attachment styles in children with autism, a learning disability, language disorder, and children with no disability. Children with autism were rated as least securely attached compared to the other clinical groups, and children with autism and a learning disability displayed less secure attachment than the children without an additional learning disability (Rutgers, Van IJzendoorn, Bakermans Kranenburg, Swinkels, Van Daalen, Dietz, Naber, Buitelaar & Van Engeland, 2007c).

Both of the aforementioned studies used the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). The Rutgers et al. (Rutgers et al., 2007c) study appears to have used this in order to establish a diagnosis of autism, whereas Naber et al. (2007) appear to have used this assessment in order to measure the severity of autism symptoms. The findings from both of these studies support the argument that children with autism and a learning disability are the least secure group compared to the other comparison groups.

The above studies sought to establish attachment in the children; however, Hoppes & Harris (1990) carried out a study involving 10 mothers of children with autism and 10 mothers with Down's syndrome children, to establish whether the mothers of children with autism described their children as being less strongly attached than those with Down's syndrome, and to what extent the decreased responsiveness that their child with autism demonstrated might reduce maternal gratification. The mothers of the autistic children experienced their relationship with their children differently to those with children with Down's syndrome. These mothers perceived their children to be less strongly attached and less capable of intimacy, and reported their children to be significantly less responsive and less expressive of attachment and emotional closeness than the mothers of children with Down's syndrome. This resulted in mothers' gratification in their relationship with their children being related to the extent to which they perceived their children as expressing emotional responsiveness, attachment and reciprocity towards them. Interestingly, they also found that the children's responsiveness was viewed by mothers to increase with age. A more recent investigation of 76 mothers and 30 fathers in the USA sought to determine the relationship between parents' perceptions of their young children's attachment to themselves and their own emotional attachment to their children, based upon their perceptions of child attachment. It also sought to examine this construct in relation to parenting stress, parents' perceptions of their children's functional impairment and their competence as parents (Goodman & Glenwick, 2012). This study employed seven different questionnaires which parents completed independently. The overall results established that parents' perception of their emotional attachment was not related to their perception of their children's attachment to them, but was related

to the other aspects of parenting such as stress and competence. There was also confirmation of a correlation between the mothers' emotional attachment and their perception of their children's functional impairment. The aim of this study was to explore parental perceptions, and although the results revealed thought-provoking and significant findings in this field where there is a paucity of research, they did not use any qualitative methods of enquiry which may have given a more in-depth interpretation of the perceptions of these parents.

In essence, although the research supports the proposition that even children with autism do demonstrate attachment behaviours, albeit less so than other children, children with autism and a learning disability are the least securely attached. Likewise, some mothers do not perceive their children to be attached to them, for a variety of different reasons, but this may be due to the limited signals given by their children. There still, however, remains limited understanding regarding this notion.

Although these studies included some definition of the diagnostic criteria they used, there appears to have been lack of evidence regarding the strict definition of autism between the studies. The chronological ages of the children included in the Naber et al. (2007) and the Rutgers et al. (2007c) studies ranged from 30.4 months to 69 months and the studies used the SSP (Ainsworth et al., 1978), which was originally developed to measure attachment in children between the age of 12 and 21 months who were typically developing. Nine out of the ten quantitative studies described in the Rutgers et al. (2004) study used a modified version of the SSP; however, there was no explanation in this meta-analytical review as to how this was modified. Two of the studies (Naber et al., 2007; Rutgers et al., 2007c) used the ADOS (Lord et al., 2000), although

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neither of these studies describes how they measured the child's level of expressive language, which is imperative when deciding on the most appropriate ADOS module to use. The ADOS includes four modules (assessments), each requiring just 40 to 60 minutes to administer. The individual being evaluated is given only one module, selected on the basis of his or her expressive language level and chronological age. Although the Hoppes & Harris (1990) study demonstrates a correlation between maternal perceptions and maternal gratification, no objective measures were used to explore the mother's relationship with her child. Nor did this research measure the child's cognitive skills, reciprocal communication and reciprocal interaction skills.

5.4.2 Joint attention and communication

An impairment in social communication and reciprocal social interaction is essential for a diagnosis of an autism spectrum disorder, and by definition all individuals with autism will display a deficit in their language, communication and interaction skills (WHO, 1992; A.P.A., 1994). The following section discusses the difficulties that children may present with in their joint attention and communication skills, and the implications of these difficulties for the relationship.

5.4.2.1 Joint attention and engagement

Joint attention is achieved when one person alerts another person to an object or action by means of eye-gazing, finger-pointing or other verbal or non-verbal

indication. Shared engagement is achieved when the child and communication partner are engaged in the same activity. The role of joint attention and shared engagement has been the focus of much debate in studies carried out within the field of autism, and analysis of home videos of children before they were diagnosed with autism concluded that the best discriminators of difficulties with joint attention at a young age included impairments in eye contact, a reciprocal social smile, facial expression and attention (Adrien, Lenoir, Martineau & Perrot, 1993). Charman (2003) argues that impairments in joint attention and shared engagement behaviours are often the earliest difficulties noticed by parents in children with autism, and become apparent around the end of the first year. In a prospective study Ozonoff, Iosif, Baguio, Cook, Hill, Hutman, Rogers, Rozga, Sangha, Sigman, Steinfeld & Young (2010) found that behavioural signs of autism, which included the frequency of gaze, shared smiling and vocalisations directed to another person, were not present at birth but developed throughout the first 12 months of life and resulted in the regression of key social communication behaviours.

The development of joint attention begins with the infant using gestures such as proto-imperative pointing which is when a child points in order to obtain an object or event, which is followed by the joining and coordination of attention in order to focus their attention with another person (Travis & Sigman, 1998). Mundy, Sigman, Ungerer & Sherman (1986) suggest that these behaviours occur less frequently in children with autism than in either typically developing infants or those with developmental delay. Children with more significant intellectual disability and autism were also found to have more challenges with joint attention (Smith & Ulvund, 2003; Mundy, Block, Delgado, Pomares, Van Hecke & Parlade, 2007).

The development of joint attention, language and communication are without doubt intertwined. Several studies have suggested that as infants develop joint attention there is a unique contribution to the development of language and communication skills (Wimpory, Nicholas & Nash, 2002; McDuffie, Yoder & Stone, 2005; Toth, Munson, Meltzoff & Dawson, 2006; Smith, Mirenda & Zaidman-Zait, 2007).

5.4.2.2 Communication

The presentation of social communication difficulties can manifest itself in an atypical acquisition of language and non-verbal communication skills, delay in the development of language or the absence of language. Typically developing infants develop the use of gesture in order to communicate at around the age of nine months, prior to which turn-taking episodes of face to face interactions occur in which the mother and baby share affect (Travis & Sigman, 1998). The use of gesture such as proto-imperative pointing to obtain an object or an action is followed by proto-declarative pointing, which differs from proto-imperative pointing as it is when an infant points to show something to another person without gaining anything tangible, but in which the infant shares or joins attention with the mother in order to be sociable. Infants with autism often use these types of non-verbal communications, especially joint attention, less frequently than typically developing infants (Mundy et al., 1986)

The incidence of children remaining non-verbal into adulthood is generally reported to be between 25% (Sigman & McGovern, 2005) and 50% (Peeters & Gillberg, 1999), and it has been suggested that these children may also have

significant difficulties or may be severely limited in their ability to communicate using augmentative communication systems (Seal & Bonvillian, 1997), and even with early intensive intervention some children may fail to develop any useful speech (Tincani, 2004).

Therefore the absence or delay in the development of joint attention and engagement as well as language often gives reason for concern in parents of children with autism when considering their child's development (Wetherby, Woods, Allen, Cleary, Dickinson & Lord, 2004). Language proficiency is suggested as one of the most important variables in predicting outcome in autism (Venter, Lord & Schopler, 1992) and therefore, because the language deficit can be so disabling, and the acquisition of language so important for outcome, there is anecdotal evidence that parents often focus upon the development of language as a main priority without understanding the importance of non-verbal communication skills.

5.5 Dyadic interactions between the mother and her child

As already discussed, children with autism do form attachments, albeit differently to typically developing children, with their parents, but children with autism do not always support their difficulties with language by using non-verbal communication skills such as pointing, gestures and eye contact, and therefore may appear not to share attention with their mothers. The interpersonal relationship between a mother and her child is built upon the ability of the child to communicate and socially respond to his/her mother. However, these building blocks of relationships are known to be impaired in children with autism

and, as Mundy and Sigman (2006) have suggested, young children with autism have an impaired capacity for relationships due to their inability to initiate and respond to exchanges of joint attention and shared engagement.

Studies which have investigated social interaction between the mother and her child indicate that children with autism are less likely to initiate an interaction than typically developing children (Sigman et al., 1986; Sigman, Kasari, Kwon & Yirmiya, 1992). Studies of parent-child interaction have also shown that children with autism regularly fail to engage with and respond to another person (Sigman et al., 1986; Dawson et al., 1990; Sigman et al., 1992). These limitations may have a considerable impact upon the parent in developing a to and fro interaction with their child (Spiker, Boyce & Boyce, 2002). Travis and Sigman (1998) carried out a systematic literature review in which they explored the difficulties that these children have in demonstrating emotions and understanding and responding to others' emotions, and the impact of these social impairments upon the relationships that these children developed with others. The studies included relationships with parents, siblings and peers, and in conclusion state that despite the social impairments that these children present with, they do nevertheless succeed in developing social relationships.

A significant body of research exists which has investigated the interactions between mothers and their children and has included typically developing children, developmentally delayed children, language impaired children and children with autism (Osofsky, 1976; Dawson et al., 1990; Doussard-Roosevelt, Joe, Bazhenova & Porges, 2003; Warreyn, Roeyers & De Groote, 2005; Meirsschaut, Roeyers & Warreyn, 2010). Early investigations of mother-infant interaction sought to examine the effects of infant development on the mother-

child interaction. Consistent relationships were found between the infant and maternal behaviour and, as Osofsky (1976) argues, more alert and responsive infants resulted in more responsive and sensitive mothers.

An empirical study of 16 children with autism compared to 16 typically developing children sought to explore children's social behaviour, affect and use of gaze during naturalistic interactions with their mothers, and found that autistic children were less likely to combine smile and eye contact in order to convey intent with their mothers, and were far less likely to smile in response to the mothers' smiles compared to the typically developing children (Dawson et al., (1990). Interestingly, the mothers of the autistic children smiled less in response to their children's smiles.

Maternal behaviours have also been investigated as a factor influencing the reciprocal mother-child interaction and the responsiveness of the child. In a comparison of autistic and non-autistic mother-child dyads Doussard-Roosevelt et al. (2003) explored whether mothers of young autistic children adapted their interaction style in order to meet the needs of their children. This study included a contingency profile which examined the child's behaviours in response to the maternal approach behaviours. Results indicate that the number of approaches between mothers of the autistic children and mothers of the non-autistic children did not differ; however, qualitative differences were apparent in that the mothers of the autistic children used more frequent physical approaches and fewer social verbal approaches. Although this study classified the autistic children as being verbal or non-verbal, this was based upon maternal report alone and no independent measures were used in order to assess the children's level of verbal ability.

An empirical study which explored emotional availability during parent-child interaction, and included 45 preschool boys with autism, examined the child's level of functioning and severity of diagnosis along with maternal factors such as parenting stress and psychological distress (Dolev, Oppenheim, Koren-Karie & Yirmiya, 2009). They sought to explore the child's impact in relation to the mother's report of impact and psychological distress. Within group differences of children with high functioning compared to low functioning autism were examined to explore maternal and child factors which contribute to the variability in mother-child interaction. Four mother scales included: sensitivity, structuring, non-intrusiveness, and non-hostility, and the child scales assessed responsiveness to and involvement of the parent. Findings showed that high functioning children demonstrated higher levels of responsiveness to and involvement of their mothers compared to lower functioning children. The mothers of the higher functioning children showed more ability to structure the interaction and use non-intrusive techniques than the mothers of the lower functioning children. Therefore in summary they suggest that the children's responsiveness and involvement may have had a positive effect, both upon the mothers' behaviour and their positive feelings towards their children. Mothers who reported higher levels of distress were also found to be more intrusive in their interactions and this may be a way in which mothers express their emotional distress.

Meirsschaut et al. (2010) explored the social interactive behaviours of mothers with their young children with autism and their interactive behaviours with an unfamiliar child. They also explored the association between a mother's interaction style and the specific social behaviour of her child and a strange child. They suggested that social behaviours are bidirectional and are

dependent upon the interaction partner approach behaviours. Interestingly, they found that children with autism did not show any different or better social interaction behaviours with their own mothers than they did with the stranger.

There are certain limitations with several of these studies. Travis and Sigman (1998) used attachment theory and maternal sensitivity to measure and describe the quality of the relationship; however, as already discussed, attachment theory does not encompass the whole relationship. It is also difficult to ascertain how these authors set the criteria for inclusion in this literature review, as no information is given regarding numbers, methodologies, validity and reliability. Dawson et al. (1990) observed the mother-child interaction in a laboratory setting, which for some young children with autism may have been distressing, and this study failed to include any assessment of the children's cognitive ability, and therefore it is unclear whether the difficulties experienced by the children with autism were due to core deficits due to their diagnosis of autism, or were due to any additional learning disability. This is also an issue in the Doussard-Roosevelt et al. (2003) study, which classified the autistic children as being verbal or non-verbal; this was based upon maternal report alone and no independent measures were used in order to assess the children's level of verbal ability.

Despite these limitations, the implications of the social delay or deficit that these children display with their mothers, along with possible differences in parenting styles and sensitivity to these difficulties, do result in difficulties with parent-child interaction and therefore possibly also with the mother-child relationship.

In the following section the quality of the relationship mothers developed with their adolescent children with autism will be discussed. Although this group

differ in terms of age from the children in the present study, these studies nevertheless support the understanding of the dynamics of this relationship. This is followed by a discussion of loss and grief and its relation to having a child with autism.

5.6 Mother-child relationships in adolescents and adults with autism

Five quantitative studies were identified which investigated the quality of the mother-child relationship in adolescents and adults with autism (Greenberg, Seltzer, Hong & Orsmond, 2006; Orsmond, Seltzer, Greenberg & Krauss, 2006; Lounds, Seltzer, Greenberg & Shattuck, 2007; Smith, Greenberg, Seltzer & Hong, 2008; Taylor & Seltzer, 2010). These studies sought to examine the complex attributions that the mothers and their adolescent/adult autistic children had upon the mother-child relationship. They included maternal characteristics such as affect, maternal warmth, expressed emotion, burden, depression, anxiety, pessimism and the mother's perceptions of the quality of the relationship with her child. Child characteristics included autism symptoms such as reciprocal social interaction and communication, co-morbid diagnosis of an intellectual impairment and behavioural difficulties.

Two different measures of maternal perception and four different measures of child features were used in these studies (see table 5.1 for an overview of the measures used in each study).

Table (5.1) Adult and child measures used

Measure	Author
Positive Affect Index (The Positive Affect Index is a self-report questionnaire in which the mother rates her feelings of positivity towards her adolescent or adult child, and the extent to which she perceives that her child reciprocates these feelings) (Bengtson & Schrader, 1982)	(Orsmond et al., 2006; Lounds et al., 2007; Smith et al., 2008; Taylor & Seltzer, 2010)
The five minute speech sample (The mother speaks for five minutes about her relationship with her child which is then coded for maternal expressed emotion) (Magaña, Goldstein, Karno, Miklowitz, Jenkins & Falloon, 1986)	(Greenberg et al., 2006; Smith et al., 2008; Taylor & Seltzer, 2010)
The Autism Diagnostic Interview: ADI-R (This is a standardised measure which is carried out during an interview conducted with the primary caregiver. The items are based on the diagnostic criteria from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)(Lord, Rutter & Couteur, 1994)	(Greenberg et al., 2006; Orsmond et al., 2006; Lounds et al., 2007)
The Vineland Screener (Establishes the level of adaptive behaviours e.g. ability to carry out grooming, dressing, etc.)(Sparrow, Carter & Cicchetti, 1993)	(Greenberg et al., 2006; Orsmond et al., 2006; Lounds et al., 2007; Smith et al., 2008; Taylor & Seltzer, 2010)
The Wide Range Intelligence Test (Carried out by a qualified clinical psychologist in order to establish intellectual disability.(Glutting, Adams & Sheslow, 2000)	(Greenberg et al., 2006; Orsmond et al., 2006; Lounds et al., 2007; Smith et al., 2008; Taylor & Seltzer, 2010)
Problem behaviours subscales of the Scales of Independent Behavior - Revised (SIB-R) (Behaviour difficulties were assessed using this instrument) (Bruininks, Woodcock, Weatherman & Hill, 1984)	(Greenberg et al., 2006; Orsmond et al., 2006; Lounds et al., 2007; Smith et al., 2008; Taylor & Seltzer, 2010)

Orsmond et al. (2006) found that there was a wide range of variability in the quality of the mother-child relationship. The characteristics of the child and the mother were predictive of the most positive mother-child relationships. These included less severe maladaptive behaviours and fewer social impairments as well as less pessimism from the mother. Smith et al. (2008) found that mothers' perceptions of the quality of the relationship with their children were associated with the children's behaviour difficulties and the autism symptoms, specifically the repetitive behaviours. Greenberg et al. (2006) also identified that high levels

of expressed emotion (a measure of emotion defined by high levels of criticism and/or marked emotional over-involvement expressed by a family member about another family member with a disability) were related to increased levels of maladaptive behaviour and more severe symptoms of autism. They also argued that the autism symptoms influenced the level of maternal expressed emotion. Taylor & Seltzer (2010) reported that the mother-child relationship improved during the later school years, possibly due to the support that is offered whilst an adolescent child is in school, particularly in adolescents who had autism but did not have an additional intellectual disability. However, this improvement slowed or stopped once the child had entered adult services. Of particular interest was the investigation of whether autism symptoms, such as difficulties in communication and reciprocal social interaction, and an additional intellectual disability had an impact upon the quality of the mother-child relationship. Two studies (Orsmond et al., 2006; Smith et al., 2008) evidenced the influence of child symptoms upon the mother; specifically, the child's impairments in reciprocal social interaction resulted in lower levels of maternal praise (Smith et al., 2008) and less severe maladaptive behaviours, and less severe social impairments demonstrated higher levels of relationship quality (Orsmond et al., 2006).

However, there appears to have been a lack of independent or objective verification of autism symptomology and impairment as the ADI-R is a parental interview and therefore offers a subjective view of symptomology. There are limitations with regard to not only these individual studies but also the applicability to the present study. These studies involved individuals who were adolescents or adults, unlike the present study which involved young children, and therefore the mother-child relationship had had many years to become

established. These studies also involved adults with autism who remained living at home with their mothers and therefore may have had an existing good relationship.

5.7 Loss and grief

The diagnosis of autism for some parents is often received with relief as professionals acknowledge their fears and difficulties. However; once this initial relief fades and the realisation of future difficulties ensues, parents often experience devastation, helplessness and loss (Nissenbaum, Tollefson & Reese, 2002).

It is commonly understood that there are five discrete stages of grief and loss experienced when someone undergoes a loss, bereavement, a major personal change or a trauma. The terminology loss or bereavement refers to the loss experienced by impending or actual death, and a five stage model was first proposed by Kubler-Ross (1997), who suggested that people experience denial, anger, bargaining, depression and acceptance. It is also suggested, however, that these steps are not necessarily experienced in full or in any chronological order but that there will eventually be a form of acceptance (Kubler-Ross, 1997).

Parents who experience the birth of a child with a disability are also described as experiencing a similar type of loss and grief for the child they thought they might have had, as well as their hopes and plans for the future of this child. This type of grief however is referred to by Bruce and Schultz (2001) as non-finite

grief, as this captures the reality of continuing and repeated loss experienced by these parents.

In a longitudinal study carried out by Bruce and Schultz (2001), they identified that parents of children with a developmental disability experienced grief which continued throughout the lifespan of the parent and the child rather than ever reaching the stage of acceptance as described by Kubler-Ross (1997).

Bruce and Schultz (2001) suggested that as time passes there are often triggers in the child and the environment which may accentuate the loss. This may be experienced by a mother if her child has ongoing difficulties with social interaction and communication as the language of his/her siblings or peers develops beyond that of her autistic child. Bruce and Schultz (2001) also suggested that as the source of the grief never leaves, grieving is an ongoing emotion experienced throughout the child's life, and as the mother is often the main carer, and therefore may spend more time at home with the child, she is faced with the loss on a daily basis. This never-ending grief is therefore different from the traditional five stage model of grief as the child remains in the presence of the parent.

The concept of loss experienced by the caregivers of patients with a chronic illness has demonstrated that personal loss, in terms of the way they, the caregivers, see themselves, and the role in which they expected to find themselves, is often vastly different than what they experience. This includes their experience of the role of motherhood (Powell-Cope, 1995; Lev & McCorkle, 1998). Moorey (1995) suggests that the identity of the caregiver can be eroded as the opportunity to engage in this role is not met, which may lead to the relationship being jeopardised. Indeed, it is suggested that when the role

that the mother imagined does not materialise, feelings of helplessness and loss of control may ensue which may result in a loss of self (Ray & Street, 2007).

5.8 Summary of the literature

This literature review has demonstrated that the exploration and description of the mother-child relationship involves many different maternal, child and dyadic dimensions and is an extremely complex phenomenon. There are many dimensions to any relationship and, as Hinde (1979) points out, it is not possible to explore or measure a relationship by simply commenting upon the interactions observed between the two participants. There are also arguably many different factors which may impact upon this relationship, and for some mothers certain factors will have a more significant impact than others. For example the child's difficulties in joint attention and shared engagement may have a considerable impact on how the mother perceives the relationship.

Mothers reportedly tend to be the primary caregivers of young children with autism (Konstantareas et al., 1992) and therefore the majority of studies involving young children with autism have naturally included mothers. Because of this, mothers may also be the caregivers who are faced with the most challenges on a daily basis. During the assessment and diagnosis of young children with a possible autism spectrum disorder and the subsequent implementation of interventions in the early years, the focus of attention is generally upon the child. However, very little thought, if any, is given to the mother and the development of the relationship with her young child during this

challenging period. The implications with regard to the difficulties she may experience with this relationship may have an impact upon how able she is to engage in interventions.

It is evident from the literature that there is a significant dearth of published research relating to the exploration of the relationship of mothers with their young, non-verbal children with autism. Several studies have focused upon different factors which may have an impact upon the relationship, such as attachment (Ainsworth et al., 1978; Bowlby, 1980; Seskin, Feliciano, Tippy, Yedloutschnig, Sossin & Yasik, 2010b; Goodman & Glenwick, 2012), maternal stress (Benson, 2010; Lyons et al., 2010; Ingersoll & Hambrick, 2011), loss and grief (Bruce & Schultz, (2001), difficulties with joint attention and engagement (Smith & Ulvund, 2003; Dawson et al., 2004; Mundy et al., 2007; Adamson et al., 2009), communication (Landa et al., 2007), and reciprocity (Rutgers et al., 2007b). Although these studies are of vital importance they do not specifically explore the impact of these factors upon the mother-child relationship. There are, however, a limited number of studies exploring the relationship of mothers with their adolescent or adult children with autism (Greenberg et al., 2006; Orsmond et al., 2006; Lounds et al., 2007; Smith et al., 2008; Taylor & Seltzer, 2010), and whilst these studies should be treated with caution in regard to their transferability to the group of mothers in this study, they are nevertheless of value.

The difficulties that children with autism present with may have a significant impact upon the mother. It may be extremely difficult, confusing and complicated for the mother to understand these difficulties, and it may appear to the mother that her child is purposefully avoiding interacting or communicating

with her. Many mothers may have preconceived ideas of the role of motherhood and all that this role entails. These may have shaped her identity as a mother and would have developed prior to the birth of her child. These ideals may have continued throughout the early months of her infant's life prior to her realising her child had difficulties, subsequently influencing and shaping her perception of her maternal role and the relationship she may have had.

The aim of this study was to explore the relationship mothers develop with their young non-verbal children with autism using a naturalistic methodology, and therefore gaining an in-depth insight into mothers' emotions and experiences. The aforementioned concepts/core relationship components were reflected upon when exploring the relationship. This will advance the knowledge with regard to this phenomenon and may bridge the gap between theory and practice for practitioners who engage with these mothers.

In the following chapter the methodology and methods of data collection will be discussed and a rationale for these decisions will be presented.

CHAPTER SIX

METHODOLOGY AND METHODS OF DATA COLLECTION

The previous chapters reviewed the key literature relating to the factors associated with the mother-child relationship.

6.1 Introduction

This chapter provides an in-depth account of the philosophical paradigm, which places the research within an ontological position, the case study methodology adopted and the various methods of data collection used to triangulate the data and the findings. This chapter also sets the scene for this study and includes details of participants and recruitment, the diagnostic pathway utilised within the study site (NHS Central Lancashire which became Lancashire Care NHS Foundation Trust during this study), and the specific interventions used with these dyads. The procedure for the analysis is discussed which is followed by a discussion about the methods used to establish rigour, and the ethical considerations have also been addressed. This chapter is divided into eight sections: *the world view and methodology, setting the context, interventions, data collection, procedure, the analysis plan, establishing rigour* and *ethics*.

As already discussed in chapter one page five, the aim of this study was to undertake an in-depth exploration of the relationship that mothers have with their young non-verbal children with autism who were using PECS (chapter 3.5.1 p. 21), and where the mothers had attended a National Autistic Society EarlyBird course (chapter 3.5.2 p. 25). This was achieved using six in-depth

case studies, each involving a mother and her young non-verbal child with autism. The data was generated using interviews, observation of mother-child interaction and a standardised questionnaire.

6.2 The worldview and methodology

This section provides an overview of the worldview which underpins the study and justification for the chosen methodology. This is followed by a description of the data collection methods.

6.2.1 The philosophical paradigm or worldview

When embarking upon any study the question of which is the best way to investigate the research problem is at the forefront of the researcher's mind. Traditionally, researchers commonly approach a research problem by following either a quantitative or qualitative pathway, with their study being underpinned by a philosophical paradigm or worldview. This worldview isolates the traditional, objective and deductive construct of positivism, in which knowledge gained is objective and derived from direct observation of measurable variables and facts. Therefore any 'invisible' entities are rejected. It is argued that quantitative measures are unable to fully capture the meaning of behaviours and thoughts, and quantitative research does not allow for the influence that the researcher may have upon the research (Robson, 2002).

This is compared to the subjective, informal and inductive construct of naturalism or interpretivism (Frey, 1994; Miller & Fredericks, 2002; Creswell &

Plano Clark, 2007) in which social phenomena are suggested to exist in the minds of people and their interpretation of those phenomena (Robson, 2002). Naturalism views reality as being socially constructed and suggests that the role of the researcher is to understand and interpret the multiple social constructs of meaning and knowledge of the participant (Miller & Fredericks, 2002; Robson, 2002). This is accomplished by using techniques such as interviews and observations rather than the traditional measures (e.g. questionnaires, surveys) typically used by quantitative researchers.

The common elements of these different worldviews include: ontology (what is the nature of the reality), epistemology (whether and how valid knowledge about reality can be achieved), axiology (the values e.g. unbiased or biased) and the methodology (deductive or inductive) (Tashakkori & Teddlie, 2003). Purists would argue that the positivistic and naturalistic worldviews, and therefore the elements of these worldviews, cannot be mixed. However, recent thinking proposes a pragmatic stance in which the research questions allow the mixing of the worldviews, and equally therefore the triangulation or integration of the methods of data collection (Bryman, 1988). Creswell & Plano Clark (2007) argue that in a triangulation design (see chapter 6.2.5. p. 83), where there is concurrent collection of data, pragmatism should be used as an 'umbrella' paradigm, but may be naturalistic but include an element of quantitative data.

The naturalistic paradigm therefore acknowledges that social phenomena exist in the minds of people and their interpretation of those phenomena and multiple realities exist (ontology). Researchers adopting this approach openly acknowledge that there may be bias (axiology). Qualitative measures capture the real meaning of behaviours and thoughts; quantitative measures may be

used to enhance the description of the results or the identification of salient themes (Creswell & Plano Clark, 2007).

As a speech and language therapist working in the natural family environment with mothers and their children and attempting to explore and understand this complex construct, I acknowledge the ontological and epistemological perspectives of both positivism and the naturalistic worldview however, Erlandson (1993) proposes that

> 'the purpose of research inquiry is to 'resolve' the problem in the sense of accumulating sufficient knowledge to lead to understanding or explanation' (p.43).

Therefore this suggests that a more 'pragmatic' stance be adopted in the search for better understanding of a phenomenon. Creswell & Plano Clark (2007) also suggest that a false dichotomy exists between qualitative and quantitative approaches, and that researchers should make use of both in order to understand a social phenomenon. I therefore have adopted a pragmatic worldview for this study which incorporates the perspectives of both worldviews. However, fundamentally I embrace a naturalistic perspective in order to enable the rich in-depth understanding and exploration of this phenomena within the natural setting. A host of factors may influence the relationship of the mother with her child, and it was believed that it would be appropriate and holistic to explore this phenomenon using an array of sources that explore different aspects of the relationship, the findings of which could be the subject for future quantitative enquiry. Hancock & Algozzine (2006) suggest that a naturalistic methodology allows for the emic in-depth exploration of the mother's relationship from the perspective of the participant rather than that of the researcher.

In deciding which naturalistic methodology to use for my study the following approaches were considered:

An **ethnographic study** seeks to investigate culture and social groups in order to describe the values, beliefs and attitudes (Robson, 2002). The researcher must spend an extended time period within this group immersing themselves within the culture. This would not have been possible due to the time restraints of this study. This type of study may also not have elicited the meaning of the mother's relationship with her child.

A **grounded theory study** seeks to create a theory which explains an action, interaction or process (Glaser & Strauss, 1965). The researcher starts from the point of no prior understanding of the phenomena. This would not have been appropriate within this study as I have extensive prior knowledge of autism having worked within the field for many years.

6.2.3 Case study methodology

This allows for the empirical investigation of a phenomenon within its real-life context and normally involves multiple methods of data collection in order to explore the phenomenon (Yin, 2003). Case study methodology allows for intensive analysis and description of a bounded unit (Miles & Huberman, 1994; Stake, 1995; Yin, 2003). The unit of investigation within this study includes the mother and her non-verbal autistic child, and therefore this methodology was believed to be the most appropriate for this study. This in-depth exploration of the complex relationship using a case study methodology (Stake, 1995; Yin, 2003) was ideal in order to develop theory as it allowed for flexibility and rigour

(Baxter & Jack, 2008). This approach also enabled me to explore the phenomenon under study within its natural context using a variety of data collection methods, in order to gain an in-depth understanding of the situation and the meaning for the mother of her relationship with her child. Luck, Jackson & Usher (2006) suggest that case studies are a flexible and pragmatic methodology which they define as

'A detailed, intensive study of a particular contextual, and bounded,
phenomena that is undertaken in real life situations' (p.104)

Merriam (2001) suggests that insights gleaned from case studies enable policy, procedures and future research to be directly influenced. The case study methodology is richly descriptive due to the fact that it is grounded in deep and varied sources of information (Hancock & Algozzine, 2006), and Luck et al. (2006) argue that there is no agreed set method used in case study but that methods are selected in relation to the questions being asked. Therefore a multiple in-depth case study design involving six single cases was employed for this study (Yin, 2003). Yin (2003) also suggests that the advantage of using multiple cases is to enable the researcher to understand the similarities and differences between the cases.

The case study approach can be located in either the naturalistic or positivist paradigm (Stake, 1995; Yin, 2003). However, for the purpose of this study a naturalistic paradigm was used, in which qualitative methods were adopted as the dominant approach, but methods which were more akin to a positivist approach were also used in order to gain a more detailed understanding, as well as to corroborate or refute the mother's reporting of the relationship. The purpose of using this mixed methods approach was to triangulate the data which Yin (2003) describes as

> *'The reviewing and analysing of evidence from multiple sources such that the study's findings are based upon the convergence of the information'* (p. 92)

This aimed to provide a rich and in-depth understanding of the mother-child relationship, which one type of data method would have failed to achieve.

Miles & Huberman (1994) proposed strategies for the analysis of data when using case studies and multiple sources of data, and suggested that the boundaries of each case must be defined by the context and definition which will ensure that the study remains in context. The boundaries of five out of the six cases therefore include: a mother, and her child who has a diagnosis of autism and was non-verbal at the start of the diagnostic assessment. The child had used the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) and the mother had participated in a National Autistic Society EarlyBird course (Shields, 1999) (chapter 3.5.1,p. 21 & 3.5.2, p. 25).

One case which was unlike the other cases was chosen as an unusual case (see chapter 8.6 p.207 for a full explanation of the unusual case). Miles & Huberman (1994) argue that the purpose of choosing an unusual case is not to set out to compare the relationships reported by the two groups, but to corroborate or refute the findings from the representative or typical cases. Further discussion of each case is given in chapter 8.

6.2.4 Mixing the methods

In this study a semi-structured interview, an observation of mother-child interaction and a standardised questionnaire (Parenting Stress Index, Abidin, 1995) were used to gather data. These mixed methods of data collection were chosen because using a single method of data collection, such as an interview,

observation or questionnaire alone, would not provide sufficient understanding of, and evidence for, the phenomena being explored (Tashakkori & Teddlie, 2003). In addition, the observation of actual behaviours was used to support my interpretation of the mother's reported perception of her relationship. The aim was that the strengths of each method would offset the weaknesses of the other (Tashakkori, 2006). If an interview had been the only method of data collection there would have been no opportunity to observe the mother's interactions with her child, which allowed for a more objective measure of the relationship. The Parenting Stress Index (PSI) (Abidin, 1995) questionnaire is commonly used in clinical practice, and was used in this study as an additional contextual data source to focus on the mother's experiences at different times during the diagnostic assessment. The use of this questionnaire was useful in that it allowed for simple statistical analysis using descriptive statistics of the findings, which would not have been possible with the qualitative data alone. It also allowed for the corroboration of specific findings from specific maternal and child domains included in the PSI questionnaire, which may not have been raised during the interview due to restricted time. The use of mixed methods of data collection therefore allowed for the observation of data convergence or departure of findings from all sources of the collected data.

6.2.5 Concurrent triangulation (integration) of the data

The mixed methods, concurrent triangulation model adopted for this study consists of a single phase of qualitative and quantitative data collection (Creswell, Plano Clark, Gutmann & Hanson, 2003). In this design both the qualitative and the quantitative data are collected during a one phase design

and timeframe; each data method is analysed separately but both address the same question and phenomenon. This design is used when it is essential to validate, confirm or corroborate qualitative results with quantitative findings, but with one method remaining the principal method of data collection (Creswell & Plano Clark, 2007), which in this study was the qualitative method.

An embedded design, in which a predominant method (qualitative or quantitative) guides the research, could have been chosen. However, Taschakkori & Teddlie (2003) and Creswell & Plano Clark (2007) all suggest that in the embedded design a different question than that addressed by the dominant method is addressed by the secondary method. Therefore as the methods chosen for this study all address the same question, that of the mother's relationship with her child, this would not have been appropriate.

The chosen method involved the concurrent but separate collection and analysis of the qualitative and quantitative data. The data was then merged during the interpretation and discussion phase of the research (see chapter 6.6.2, p.104 for a full discussion). No attempt was made to transform or convert one type of data into the other, as Tashakkori & Teddlie (2003) suggest there is limited guidance in the literature in relation to the conduct and analysis of these transformations. However, during the observation of the mother-child interaction, which employed a quantitative coding, a narrative of the quality of the mother's relationship with her child was also recorded. The results of the separate analysis of both the qualitative (interview and observation narrative) and quantitative (observation coding and PSI scores) data were converged using a conceptually clustered matrix developed by Miles & Huberman (1994)

(for an in-depth discussion of the conceptually clustered matrix see chapter 6.6.2, p.105).

The rationale for using this type of design was a desire to bring together the differing strengths of the interview, observational data and questionnaire, and offset the weaknesses of each of these methods. The convergence of these different sources of enquiry helped to promote the credibility, dependability and confirmability of the research and resulted in a more robust study. Figure (6.1) depicts the concurrent triangulation of the data.

Figure (6.1) Concurrent triangulation of the data
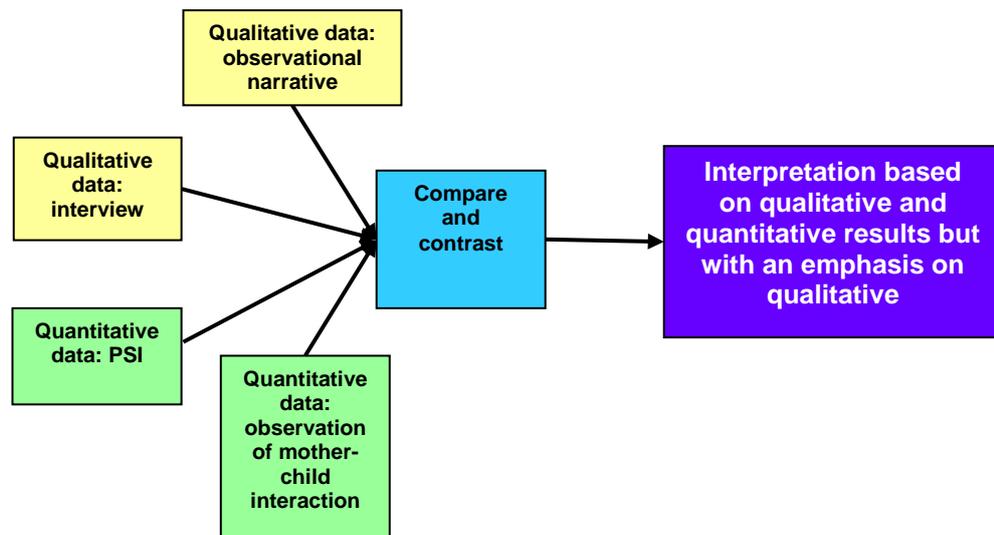
6.2.6 The style of writing

The writing style of qualitative and quantitative methods differs in that qualitative research is often written in the first person with little or no use of tables, statistics or lists, and an emphasis is put upon the narrative. Conversely

quantitative studies write in the third person in an objective manner and use many tables and lists with little narrative. The dilemma occurs therefore when carrying out a mixed methods study as to which writing style to use. This study is a naturalistic one and should therefore adopt the qualitative writing style, but due to the fact that quantitative methods have also been used an element of quantitative style has also been adopted. A mixed style of writing has therefore been adopted using both qualitative and quantitative style.

6.3 Setting the scene

This next section will describe the participants and the recruitment process, and set out the context within which the study took place. This includes a critical review of the interventions used with these dyads and a discussion regarding the professional support offered.

6.3.1 Participants and recruitment

The participants for this study comprised a purposive sample, which is described by Tongco (2007) as being a sampling method in which the researcher is not seeking to randomly select typical participants, but a subjective method where participants are chosen because of their particular characteristics and knowledge, and the research is focused upon a specific cultural domain. In the original proposal eight mother-child dyads were to be recruited. However the data collection and analysis proved to be extremely time-consuming and the data that was gathered was very detailed. Overall,

seven mother-child dyads were approached from the speech and language therapy caseload from Central Lancashire NHS Trust, and all but one agreed to participate. The mother who chose not to participate explained that she did not feel that she could discuss her feelings openly as she was struggling to come to terms with her child's diagnosis. Therefore six mother-child dyads were included in the final study (all participant details are included in chapter 7, p. 120 (pilot study) and chapter 8 (individual case studies)). No attempt was made to specifically address any issues around ethnicity or social class of any of these mother-child dyads as this was an exploration of these mothers' relationships with their children and not an attempt to attribute any findings to any social or cultural demographic interpretation. The mother-child dyads were recruited post assessment, diagnosis and intervention. All mothers were initially posted an information sheet (Appendix 2, p.339) to their home address that provided full details about the study. I then contacted each of the mothers via telephone to discuss the study, and their willingness to participate. All mothers were asked to complete a consent form prior to the start of the study (Appendix 3, p.341).

Five mother-child dyads had attended the pre-school autism diagnostic assessment pathway, and all had received a diagnosis of autism from a group of multidisciplinary professionals who were experienced in the assessment and diagnosis of autism. All of the children were non-verbal at the start of the diagnostic assessment (see chapter 6.3.2 p. 88 for a description of professionals involved). The assessment lasted between five weeks and 14 months and the dyads were seen jointly by all professionals in order to deliver a cohesive assessment and diagnosis. All of the dyads were seen for a minimum of six times throughout the diagnostic assessment by the same group of professionals, and all of the children were introduced to and used the Picture

Exchange Communication System (PECS) at the beginning of the diagnostic assessment period. All of these mothers had attended EarlyBird (Shields, 1999) which is an autism-specific parent training (see chapter 3.5.2 p. 25 for a description of EarlyBird). Figure (6.2) shows the sequence of the assessment and diagnostic pathway for cases 1-5.

The children involved in this study were all diagnosed with classic autism as opposed to high functioning autism or Asperger's syndrome as described in the ICD-10 (WHO, 1992). A detailed description of each mother-child dyad can be found in chapter 8.

Figure (6.2) The process of assessment and diagnosis for cases 1 - 5
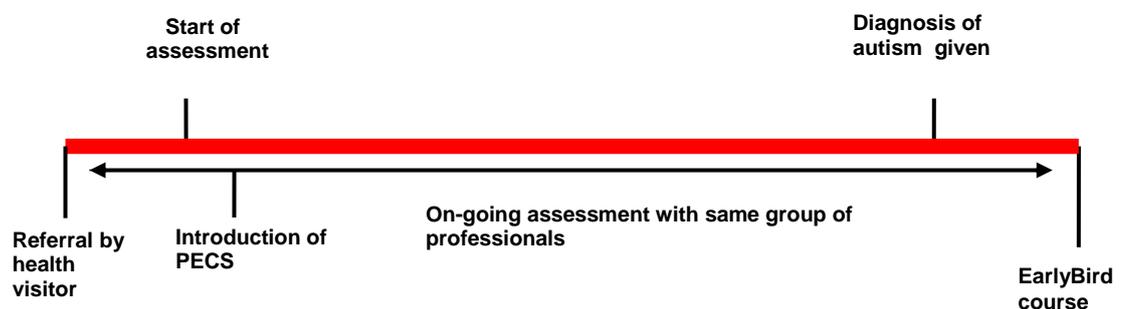
As previously identified, one mother-child dyad which was unlike the other cases was chosen as an unusual case (Miles & Huberman, 1994). This dyad attended the school-age pathway as the child's difficulties were not recognised during the pre-school years. This child was verbal at the start of the diagnostic assessment and therefore did not require the use of PECS. This mother was seen by two professionals separately during the assessment and did not receive EarlyBird training. Figure (6.3) shows the sequence of assessment and diagnosis for the unusual case.

Figure (6.3) The process of assessment and diagnosis for unusual case
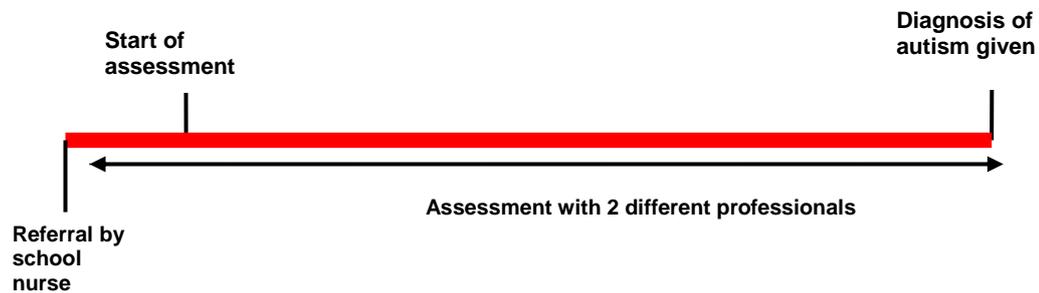
6.3.2 Diagnostic pathways in NHS Central Lancashire (now Lancashire Care Foundation Trust)

All but one of the participants involved in this study were recruited from the pre-school Social Communication Assessment Team (SCAT) Pathway. This pathway aimed to follow the guidelines of the National Autism Plan (NAP) (Le Couteur, 2003) and attempted to assess and diagnose children within the strict criteria set out by the NAP. Pre-school children were seen by a multidisciplinary/multi-agency group of professionals which included: a specialist speech and language therapist, specialist educational psychologist, consultant community paediatrician, specialist learning disability nurse and an Early Years teacher.

All of the professionals, with the exception of the Early Years teacher, were trained in the assessment and diagnosis of autism and all had considerable clinical expertise in this area and had worked in the field of autism for a minimum of ten years. Children and families were seen initially by a consultant paediatrician for a general developmental assessment which was followed by a referral to the SCAT team. Assessment was usually carried out within a timeframe of 14 weeks and all of the children were seen in a variety of settings

including the local Child Development Centre (CDC), the home setting and a nursery or social setting. Table (6.1) lists the specific autism assessments used with each child.

Table (6.1) Specific assessments used with each child

Assessments used with each child
The Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing, Leekam, Libby, Gould & Larcombe, 2002)   **or**   Clinical Practice Questions for Parental Interviewing of Children who may have Autism (Wimpory, 1992)
The Play Observation Kit (Mogford-Bevan, 2002)
Informal observation and assessment of social and communication abilities within a nursery/social setting
Home observation
Communication assessment to assess not only language but also functional, non-verbal communications
Cognitive assessment using either formal assessment or informal observation if the child was unable to cope with a formal assessment

Each family was allocated a link worker for the duration of the assessment, who acted as the family's first point of contact; however, they were actively encouraged to contact any member of the team at any point during the assessment. Families were also encouraged to participate in the assessments and if they were not able to be present for any reason, for example during the nursery visit, the link worker would make contact following the visit to give feedback.

A diagnostic or feedback meeting took place in a comfortable room with all of the professionals present. A detailed multi-professional report was presented to the parents at this meeting and copies were sent to appropriate professionals following the meeting. If a diagnosis of autism was given, parents were given a

pack with various information leaflets and an action plan for follow-up interventions, therapy and educational placement was discussed. Parents were also invited to attend the next available EarlyBird course which was run by the same professionals who carried out the assessment and diagnosis. Figure (6.4) shows the pathway for children being assessed within the NHS trust.

Figure (6.4) Pathway for Social Communication Assessment Team (SCAT)

HV or SLT concerned child may be autistic

Referral to consultant community paediatrician

General developmental assessment within 6 weeks

Suspected Autistic Spectrum Disorder

(Child referred to SCAT for multidisciplinary assessment)

Specific autism assessment

Family link worker allocated

Family meet whole team

Appropriate autism assessments carried out

Feedback given to parents by team

Multidisciplinary report given to parents

Care plan agreed between parents and professionals

Appropriate autism interventions

or

Transfer to other appropriate professional

6.4 Data collection methods and individual procedures

This section describes the methods used to collect the data and the individual processes involved, together with the rationale for their selection. Prior to the collection of any data, mothers were encouraged to look at any home videos, photographs, diaries, etc. which were pertinent to the period in question in the hope that this would refresh any memories. Data collection methods included: a semi-structured interview, an observation of the mother-child interaction and the Parenting Stress Index questionnaire (PSI). The qualitative semi-structured interview and observational narrative were the principal methods of data collection, with the numerical data (observation coding and PSI scores) being supplementary. Each individual method of data was initially analysed and was then integrated using the matrices and association networks (see chapter 6.6.2, p.104 for a full description).

6.4.1 The interview

A semi-structured interview was developed to explore, in detail, the mother's relationship with her child as well as her perceptions of the process of assessment and diagnosis (see appendix 4, p.343 for the interview schedule). The interview was developed using strategies described by Kvale & Brinkmann (2008) and Barriball & While (1994), and focused upon a number of interrelated topics that were based upon a list of mental enquiry questions (Barriball & While, 1994) listed in table (6.2). These mental enquiry questions guided the development of the most appropriate questions to be asked during the interview. The interview was designed in a way that could be flexible and

allowed the mother to discuss other issues that were important to her around the time of assessment and diagnosis.

Table (6.2) Mental enquiry questions

• Is the mother disappointed about having a child with an autism spectrum disorder?
• How do her child's difficulties with communication make her feel?
• Did she feel different about her child once they had mastered PECS?
• Did she have pre-conceived ideas about the reasons for her child's difficulties/diagnosis?
• Does she have any pre-conceived ideas about what professionals can offer?
• What type of support made the biggest difference to her?
• Does she feel that her interaction with her child has always been easy/natural?
• Are there any things that make interaction easier?
• Having gone through the process of the assessment and diagnosis has the relationship changed?
• Do the child's difficulties have an effect on the mother's relationship with other people?

Five out of the six mothers became upset during the interview, which had been discussed during the ethics interview. A further discussion about how these situations were dealt with can be found in chapter 6.9 p.117. Each interview lasted approximately two hours and was tape recorded.

6.4.2 Mother-child interaction observation

In order to make sense of a relationship and to be able to describe it accurately, the researcher must rely on the generalisation of the subjective nature of, and quality of, the interactions that characterise that relationship (Hinde, 1995). This can be achieved in some aspects through the observation of the mother interacting with her child, whilst acknowledging that this may be limited as it is not possible to observe every interaction over an indefinite time period. Therefore it was considered that a more subjective description of the mother's thoughts, feelings and values could be achieved through the interview and through the PSI questionnaire; whilst a more objective assessment would be obtained using an observation of the mother and child interactions.

The observation of the mother-child interaction was undertaken to systematically rate behaviours observed in the mother-child dyad. The essence of the analysis was to observe the mother's behaviours towards her child and gain some understanding of her relationship with her child, interpreted from the behaviours observed. In order to accomplish this it was essential to also observe the child's behaviours and how these behaviours affected the mother. The method of observation and selection of behaviours to be analysed was based upon research carried out by Doussard-Roosevelt et al. (2003), Watson (1998), Horowitz et al. (2005) and Lemanek et al. (1993).

Fundamentally there are two different approaches to direct observation which are polar extremes: participant observation and structured observation (Bakeman & Gottman, 1997). Participant observation is described as essentially a qualitative style and was originally rooted in the work of social anthropology. The key feature is that the observer seeks to become integrated as part of the

group and not only physically involves himself as a participant in the social world of the group, but also is required to learn the social conventions, verbal and non-verbal language of the group. The observer must also develop a role within the group. The observer does not remain objective and produces a narrative report regarding the observed behaviours. This type of observation is open to criticism, however, with regard to subjectivity and the judgements made by the observer. However Manis & Meltzer (1967) suggest that when working with a specific group of people, behaviours and meanings can be explained by the experiences of the observer, as the social world involves subjective meanings and experiences that are constructed by the participants in a particular social setting, and the interpretations of the meanings and experiences can only be achieved by participation within the group. This possible subjectivity also raises questions regarding reliability and validity, and how scientific rigour can be achieved. Authors including Richards & Postle (1998) and Waddington (1994) suggest that scientific rigour in an essentially qualitative technique is essential and can be achieved through heightened sensitivity to the problem of subjectivity. In order to achieve entry into the social world of the group being observed, Richards & Postle (1998) suggest that it places a considerable burden on the observer where the involvement can potentially last years. In addition to this Lincoln & Guba (1985) warn that

> *'One would not expect individuals to function adequately as human instruments without an extensive background of training and exposure'* (p.195)

Analysis of participant observation studies shows they essentially utilise a descriptive observation in which the basic aim is to describe the setting, the people and the events which have taken place. Spradley (1980) suggests nine

dimensions of descriptive observation which are used initially to give a detailed account of the event. The next stage involves developing a set of concepts or a theoretical framework which is grounded in the detail of the story and explains what is happening. A major criticism of participant observation is of course the bias which is incurred by becoming a participant or member of the group. Furthermore unstructured observation is complex and requires the observer to perform difficult tasks of synthesis, abstraction and organisation of the data (Robson, 2002).

In contrast to participant observation, formal structured approaches to the data collection and analysis impose a large amount of structure and direction on what specifically is to be observed and subsequently analysed, and therefore it is easier to achieve high levels of reliability and validity. Structured observation is described by Bakeman & Gottman (1997) as objective, as it should produce similar results no matter who is observing the behaviour, because the behaviours being observed are not subject to personal influences seen in a narrative report.

However, in imposing such a tight structure there may be loss of complexity and completeness. Structured observation requires the observer to remain detached and the observation is carried out in order to quantify behaviours.

In order therefore to achieve the aims of this study, and derive the advantages of these differing observation methods whilst mitigating the disadvantages, both types were used. Therefore a coded systematic observation schedule as well as a narrative was used. The mother–child observation took place in the local Child Development Centre where a selection of toys (see appendix 15, p.378) was placed in a room which was aimed to be distraction free. The mother was told

that the session was being video recorded as part of a PhD study and not as part of any treatment. She was reassured about confidentiality and her consent was re-confirmed. The mother was asked to play with her child in the way she normally would at home. A video of the mother and child interacting was recorded for 20 minutes. Once this was completed the mother was given positive feedback about her performance and thanked for participating. All of the mothers were anxious for feedback on their performance during the interaction; therefore, positive interactions that they used during the session were commented upon and all were given a suggestion as to how to improve a specific aspect of their child's communication. The video was immediately imported into NVivo and then forwarded for exactly eight minutes into the recording, which allowed time for the mother and child to settle into the session. The following four minutes were analysed and were viewed at least four times. Observation sheets were developed which were accompanied by definitions of the behaviours to be observed. A five point Likert scale was used to score each of the behaviours from five (extremely positive) to one (extremely negative) (see appendix 7and 8, p.360). A five point scale was used as opposed to a four point as this allowed for a behaviour to be judged as being neutral when it was neither positive nor negative. The behaviours which were observed included:
Mother's behaviours: *mother's affect, quality and amount of physical contact, quality and amount of visual contact, quality of language, quality and amount of non-verbal cues, flexibility and time spent in joint attention.* **Child behaviours:** *affect, quality and amount of physical contact, quality and amount of communicative eye gaze, quality of communicative intentions and use of non-verbal acts.*

6.4.3 Observational narrative

I recorded a narrative following each observation of the mother-child interaction. These observations included the quality of the relationship, a judgement about the reciprocity of the relationship and the mother's competence in her interaction with her child, and any other pertinent observations were recorded. These observations were recorded onto a video log which was stored on the study computer.

6.4.4 Parenting Stress Index (PSI)

The Parenting Stress Index (PSI) (Abidin, 1995) is a clinical and research questionnaire comprising 120 questions, designed as a screening and diagnostic assessment to identify salient parent and child characteristics and systems which are under stress, and the magnitude of stress in the parent-child relationship. The interpretation of the results from the PSI proceeds from considering the total stress score, the child domain subscales and the parent's domain subscales. Each individual subscale may be interpreted independently, depending upon the picture that emerges, and the relationship of each to the other. The independent subscales are as follows:

Maternal domains: Competence, isolation, attachment, health, role restriction, depression and spouse.

Child domains: Adaptability, reinforces parent, demandingness, mood and acceptability.

Of particular importance for this study were the maternal domains of **attachment, competence, depression** and **spouse** and the child domains of **reinforces parent** and **mood**. The reason for these being chosen was that these particularly related to the aims of the PhD, whereas the others did not (see appendix 13, p.370 for a full description of these domains).

The PSI was originally validated with 534 parents of mainly typically developing children in Virginia in the USA (Abidin, 1995). Parents of children with behaviour and health problems were also included. Reliability coefficients were calculated based on the responses of all the parents, and alpha coefficients were determined for each subscale. The PSI was validated with parents of children with autism in a study by Donenberg & Baker (1993) carried out in the USA, in which they found that those parents rated themselves more stressed than the group of parents with typically developing children, and that the stress was mostly child related and affected most of the subscales of the child domain.

Although the PSI has been used extensively in the UK (Salt, Shemilt, Sellars, Boyd, Coulson & Mc Cool, 2002; Aldred et al., 2004; Beck, Hastings, Daley & Stevenson, 2004) and has been validated in countries such as the USA, China, Portugal, French-speaking Canada and Korea, there have to date been no known validation studies undertaken in the UK. However, in the absence of any other instrument available to assess both parental and child domains this tool was deemed the most appropriate for this study.

The PSI was chosen for this particular research as it is easy and quick to complete, and it addresses the areas of parent-child relationship that are under stress and highlights areas of child behaviours that have an impact upon maternal behaviour and emotions. There was no other parenting stress

questionnaire found that addressed these specific child domains. The PSI has also been used extensively in previous research in this area (Lecavalier et al., 2006; Hupp, Reitman, Forde, Shriver & Lou Kelley, 2008). The PSI was posted to the mother for her to complete prior to any other type of data being collected. She was asked to complete this questionnaire based upon her present emotions. A further PSI was given to the mother to complete following the interview and she was asked to complete this one based upon her remembered/perceived emotions during the time of assessment and diagnosis. The reason for this was that during the interview the mother's memory of the emotions she had experienced during that time was refreshed.

6.5 Procedure

This section describes in detail the overall procedure of the data collection.

Data collection took place over a period of one week for each mother-child dyad and all of the data collection was completed over a seven month period (between January and July 2009). Following receipt of a posted copy of the information sheet (appendix 2, p.339), mothers were contacted by telephone in order to gain verbal consent and relay any further information about the study which was unclear. Once agreement to take part in the study had been obtained via telephone with the mother, a home visit was arranged. At this meeting, the nature and purpose of the study was clarified, and the mother was asked to sign a consent form. An initial PSI was also posted out to the mother with instructions to complete the questionnaire on her own at least a week before the arranged interview, and that it should be based upon her emotions at that time

(*later emotions*). At the home visit, the nature and purpose of the study was re-clarified and the mother was asked to sign a consent form. An interview then took place in the mother's own home which lasted approximately two hours and was tape recorded. Immediately following the interview a second PSI was completed by the mother, with instructions for her to base her answers upon earlier/previous emotions during the time of the assessment and diagnosis (*early emotions*). It was hoped that the interview would help refresh the mother's memories from around this time. At this meeting a convenient time was made to undertake an observation of the mother and her child interacting. All observations took place in the mother's local Child Development Centre and were video recorded. Following each contact with the mother a reflexive memo was written (see appendix 6, p.358). The data was collected between three and 30 months after diagnosis and EarlyBird. Figure (6.5) depicts the sequence and timing of data collection.

Figure (6.5) Sequence of data collection
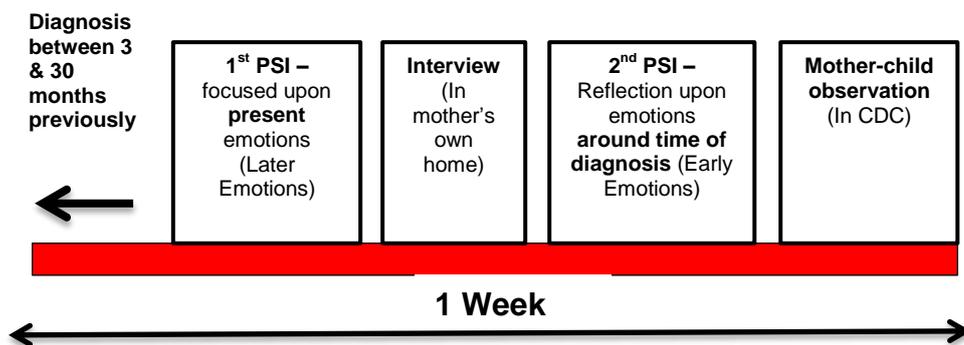
6.6 Data analysis phases

The aim of this study was to explore in depth and give a robust description of the mother-child relationship. In order to achieve this, a complex and in-depth analysis of all of the data was considered appropriate to provide authentic interpretations of the mother-child relationship. This was not an easy task and therefore, in order to ease the complexity and aid description, the analysis was divided into two phases:

Phase one involved the separate analysis of each method of data, the integration of those results using conceptually clustered matrices in order to develop themes, and the development of an association network for each individual case which is followed by a narrative.

Phase two, which was carried out after the completion of phase one, involved the development of a conceptual framework which enabled the analysis to move from the descriptive into a more interpretive, deeper level, and connected existing knowledge of relationships. This was followed by cross-case analysis of all cases using various strategies to aid the interpretation (see chapter 9, p.214 for a detailed description).

Phase one will be discussed in this chapter and phase two will be introduced and discussed in chapter 9 following the analysis of the individual cases. The analysis plan for the two phases is presented in figure (6.6).

Figure (6.6) Within- and cross-case analysis plan
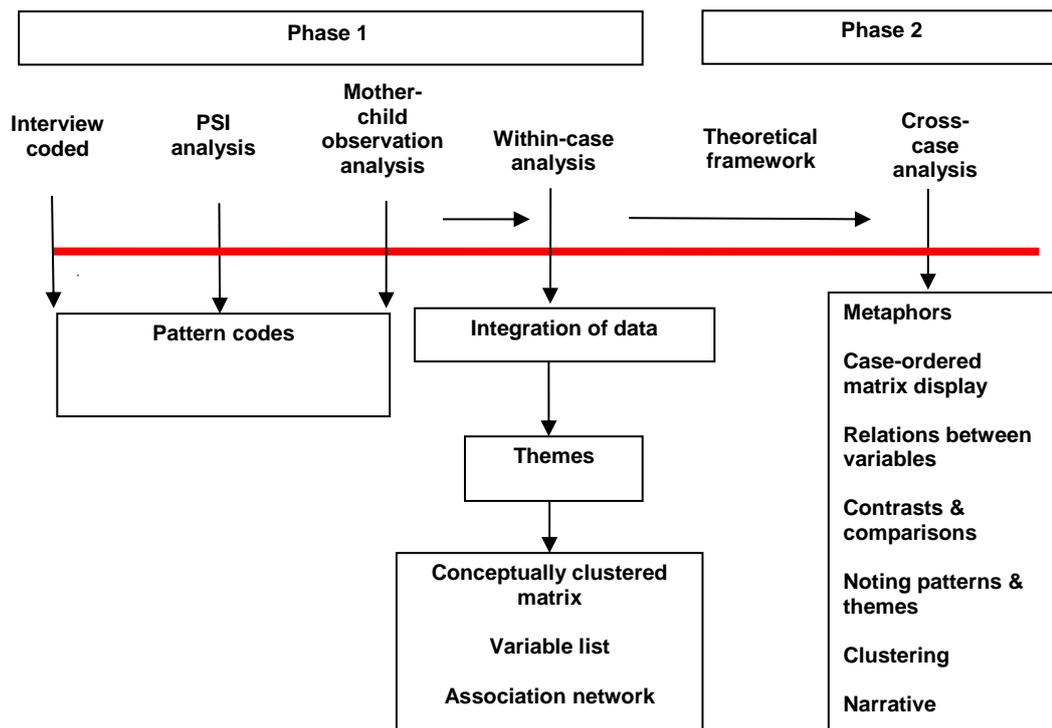
Phase one

6.6.1 Analysis of individual sources of data

The qualitative data was stored and initial analysis was aided by a computer software package called NVivo. The results of the numerical data were stored on a computer used solely for the purpose of the study in order to maintain confidentiality. No computer package was used for the analysis of the numerical data as simple descriptive statistics were used, and a programme such as SPSS was not deemed necessary.

6.6.1.1 Coding the interview data

Interviews were coded immediately after they were carried out using the guidelines given by Miles & Huberman (1994). Following the transcription of the interview the data was coded inductively using a scheme in which descriptive codes were used, and as the research progressed the codes were re-named and developed from previous interviews. These descriptive codes (an example of an inductive code would be rejection) were labels assigned to units of meaning found in the data, and were words rather than numbers as this helped to keep codes closely related to the concepts and themes. Each interview was coded several times, initially using the descriptive coding which simply described what was happening without using any interpretation. This was followed by interpretive or pattern coding (an example of pattern coding would be attachment), in which a code was attributed based on a deeper knowledge of the local dynamics and was much more inferential and exploratory. A clear, operational definition of each code and theme was kept in order that they could be used consistently over time. These definitions were improved upon and became more focused as the study proceeded.

6.6.1.2 Coding the mother–child interaction

The coding of the mother–child interaction was based upon empirical evidence from several studies in which standardised observation schedules had been developed (Horowitz, Logsdon & Anderson, 2005). These studies all focused upon the importance of responsive, contingent parent–child interactions.

During the observation of the mother-child interaction a qualitative observational narrative was recorded which reflected the interaction skills that the mother used with her child. This was included in the final within-case analysis.

6.6.1.3 Analysis of the Parenting Stress Index

For the PSI the total stress score, child domain scores and parent domain scores were calculated using percentiles which are used as standard in the PSI. These were calculated separately for *early* and *later emotions*. Descriptive statistics were used and were displayed graphically in order to demonstrate differences between *early* and *later emotions*, and to allow for easy visualisation of these differences. Scores that fell between the 1st and 15th percentile were classed as low, scores between the 15th and 85th percentile were classed as medium, and scores between the 85th and 100th percentile were classed as high. These scores are based on the normative scores which were derived from the frequency distribution of the normative sample (Abidin, 1995).

6.6.2 Within-case analysis (integration of data sources)

This particular study was designed to answer several questions (see chapter 1.3 p. 4) within each individual case study and, as Miles & Huberman (1994) point out, carrying out a separate analysis and case report for each question would not only be confusing but also tiring and lengthy to read. Therefore a method which clusters all of the results and is clearly displayed is the best solution to generate meaning (Miles & Huberman, 1994).

In this study the qualitative themes derived from the interview data and the narrative following the mother-child observation, supplemented by the numerical descriptive data from the mother-child interaction and the PSI, were integrated using a conceptually clustered matrix, a variable list and an association network (Miles & Huberman, 1994). An example of a conceptually clustered matrix can be seen in chapter 8.2, p.167).

The building of the conceptually clustered matrix follows three stages:

Stage one involves the building of the display using rows and columns which will represent each theme and the evidence for that theme.

Stage two involves entering the data to demonstrate how the themes were developed and includes: mother and child nodes which were developed from the coding of the interview data, ratings and percentiles, short summary phrases and observational statements.

Stage three involves the drawing of conclusions, using the tactics of noting patterns and themes, making contrasts and comparisons and noting relations between variables (a full description of each tactic is provided in chapter 9.4.3, p.220).

This is then followed by developing a schedule of variables for each case which is divided into antecedent, mediating and outcome variables. An example of this can be seen in table (6.3) (Each variable is independent, and the corresponding variables within each column do not relate to each other.)

Table (6.3) Schedule of variables (Sheila)

Antecedent	Mediating	Outcome
• Fear of how to handle him • Disappointment and anger at having child with difficulties • His difficulties with communication and interaction • Interaction was one-sided • Lack of confidence and competence • Having to suppress emotions • Trying to make him normal • Unable to discuss fears with partner • Feeling that communication is vital in order to have place in society	• Increased interaction • Process of assessment = gradual realisation • Diagnosis • Professionals took the burden • PECS enabled appropriate interaction • Getting down to his level • Increased understanding of autism • Interventions • Learning how to communicate and interact • EarlyBird • Ability to talk freely about emotions to professionals • Time	• Didn't feel love • Increased love • Became a better mother • Felt a failure as a mother • Better acceptance of the diagnosis • Self-blame for his difficulties • Lifted burden of guilt • Gave hope • Saw him for the first time • Accepted him for who he is • Mother and partner able to communicate

Once this variable schedule has been developed and the data is progressively focused, a map of the variables (an association network which is depicted by boxes and bubbles) and the relationships amongst the variables (which are shown by directional arrows) is constructed. This is then followed by an associated descriptive text which describes the meaning of the connections between the variables (Miles & Huberman, 1994). The integration of the qualitative and numerical data, like many other aspects of mixed methods research, can be challenging (Creswell & Plano Clark, 2007). Many texts discuss the integration of qualitative and quantitative data but few discuss the

logistical steps involved in doing so. Miles & Huberman (1994) offer extensive details in the logistics of this integration, and give several alternatives which are suitable for a variety of different types of studies.

The analysis of data within a single case allowed for the description and understanding of what was happening within the individual mother-child relationships. The aim of this study, however, was to use multiple case studies in order to observe the processes and outcomes at a deeper level, therefore developing a more complex, robust and powerful description of the relationship. In order to do this a conceptual framework was developed, based upon a theoretical framework by Hinde (1995), which was followed by the cross-case analysis and narrative (*phase two*). Phase two of this study commences in chapter 9.

6.7 Addressing rigour

In the following sections trustworthiness and how this was achieved is discussed, followed by the ethical considerations.

6.7.1 Trustworthiness

There has been much debate about the traditional or conventional positivistic view where validity and reliability must be achieved in order for a study to be of any value. However, in the field of qualitative research these concepts are arguably not helpful and, by the sheer flexible nature of social research, not achievable. Lincoln & Guba (1985) propose four different criteria to ensure the

trustworthiness of a study which include: **Confirmability**, which relates to how congruent the findings are likely to be to reality, and is equivalent to the positivistic concept of internal validity. This was achieved by using multiple sources of evidence, establishing a chain of evidence, the use of an unusual case and having several peers review the study. **Transferability** refers, in terms of the positivistic approach, to generalisation of the results to the greater population. This however is not possible in qualitative research where the numbers are small and bias is acknowledged. However, Lincoln & Guba (1985) propose that it is possible to transfer the results to similar participants or groups if sufficient contextual information is available. In this study, this was achieved by using multiple case studies. **Dependability** refers to the positivistic strategy of reliability which ensures that another researcher would be able to emulate the study using the exact same techniques. Again, Lincoln & Guba (1985) argue that this is not possible in qualitative studies as the phenomena being explored are often changing. They do suggest however that keeping clear protocol documentation goes some way to achieving this. In order to achieve dependability, I used a case study protocol (appendix 17, p.382) as well as a case study database. **Credibility** refers to the positivistic view of objectivity which again is not considered possible in a qualitative design. Miles & Huberman (1994) and Lincoln & Guba (1985), however, all suggest that it is possible to attain credibility by having the participants read and review the study prior to publication (member checking). This was not carried out in this study and the reasons for this are discussed in section 6.7.2 p. 110. In order to achieve these criteria and to ensure the quality of this study the tactics which were employed can be viewed in table (6.4).

Table (6.4) Criteria to ensure trustworthiness

Criteria	Case study tactic	Phase of research
Confirmability	**Integration or triangulation of multiple sources of evidence:** This was achieved by collecting data, using interviews, observation and questionnaires, which was triangulated.	Data collection
	Establish chain of evidence: An ongoing diary of evidence from every contact and data collection session was kept (see appendix 16, p.381) **Use of an unusual case:** Used in order to corroborate or refute findings. **Peer review of the study:** This was achieved by not only the research supervisors reading the study but also two academics eminent in the field of autism.	Data collection
Transferability	**Use replication logic in multiple case studies:** Five cases which were similar to each other were chosen in order to replicate each other. An unusual case was chosen to corroborate or refute the findings.	Research design
Dependability	**Use case study protocol:** A case study protocol was established prior to any data collection and was refined following the pilot study. This outlined the data collection procedures and the process of analysis.	Data collection
	Develop case study database: A case study database was established using a computer package (NVivo).	Data collection
Credibility	**Member checking:** it was decided that this would not be carried out and the reasons for this are explained in section 6.7.2, p.110	Following single case study analysis

6.7.2 Member checking

The sharing of the findings of the study, namely 'member checking', is a strategy used in some qualitative studies and is proposed by Lincoln & Guba (1985); however, it is not without its difficulties. As Goldblatt, Karnieli-Miller & Neumann (2011) state, it is used with the good intention of including the participants in the research, but it can nevertheless cause harm to the participants and to the relationship between the researcher and participant. Although it had been the original intention of this study to use member checking, because of the sensitive nature of this study and the emotional responses of five out of the six mothers it was decided that this would not be a

useful strategy to implement from the point of view of the mother reading a transcript of her own narrative.

6.8 Potential bias

Bias is defined as

> *'a deviation of results or inferences from the truth, or processes leading to such deviation'* (Hassan, 2006)

Hassan (2006) describes bias as the lack of internal validity, which is of central importance to a study. Various threats to the credibility of a study using a flexible design are possible, and Guba, Lincoln & Denzin (2008) suggest dividing these possible threats into three broad categories: respondent bias, reactivity and researcher bias. As bias was a real potential threat throughout this study, specific strategies were adopted in order to attempt to mitigate any bias. These are discussed as follows:

6.8.1 Respondent bias

Respondent bias can take on various different forms; particular to this study, potential threat could result from social desirability bias and recall bias. A description of these biases and how they were addressed during the study is presented below.

6.8.2 Social desirability and recall bias

Social desirability bias is defined by King & Bruner (2000) as:

> *'The pervasive tendency of individuals to present themselves in the most favourable manner relative to prevailing social norms'* (p.80)

As the study questions may have been perceived to question the competence of the mother, it was essential to recognise the threat of the mother answering questions in the most favourable way. In this study, this was a potential threat for both the interview and the PSI questionnaire.

Whilst the PSI questionnaire used in this study was standardised, and has therefore been subject to internal validity and reliability to test the readability of the items, the relevance of the content with the given group the PSI is used with, and the adequacy of this construct, the potential for social desirability remained a threat.

Another potential threat to the validity of this study is the possible difficulty for some mothers of recalling information from up to two years previously. As Hassan (2006) suggests, recall bias presents a major threat to the internal dependability and credibility of a self-report study and can result in the reporting of inaccurate information.

The approaches used in order to minimise the effects of both recall bias and social desirability bias in this study were:

- Mothers were asked to look at any home videos, photographs, diaries, etc. which were pertinent to the period in question, prior to any data collection.

- In order to minimise recall bias the interview was carried out prior to the completion of the second PSI questionnaire. This questionnaire was aimed at reflecting the mother's emotions around the time of assessment and diagnosis and it was hoped that the interview would result in her reflecting back to this time.

- The accurate articulation of the study questions, the interview technique, the process of deeper probing in order to prompt the mother for accurate information and the personal rapport between the mother and the researcher are believed to help in the potential elimination of recall bias and social desirability (Hassan, 2006). All these methods were adopted during the interview process.

6.8.3 Reactivity and the Hawthorne effect

The Hawthorne effect can be broadly defined as

'the change in behaviour during the course of an experiment which is altered by a participant's awareness of participating in the experiment' (Merrett, 2006)

As this study involved the observation of the mother-child interaction, there was the potential of bias due to mothers altering their behaviour. In order to mitigate this form of bias the following strategies were used:

- Reassurance that the video observation remained confidential.

- Reassurance to the mother that her behaviour during the observation was not being judged but was being used simply to assess the interaction between her and her child.

- During the observation I attempted to remain in the background, and be unobtrusive.

6.8.4 Researcher bias

Quantitative research has been at the forefront of the development of objectivity and detachment during the process of any study, and quantitative or positivist researchers constantly strive to minimise bias which influences the study domain. However, Jootun, McGhee & Marland (2009) state that no study is carried out within a bubble without the influences of extraneous factors. Each person has values that are a result of several factors which include personality, socio-economic status, and culture (Porter, 1993). Ahern (1999) also states that it is not possible for qualitative researchers to be totally objective, because total objectivity is not humanly possible.

Therefore an effort must be made to attempt not to allow one's own values and judgements to shape the collection and analysis of the data. This will be attempted through a process called reflexivity, or more precisely reflexive bracketing (Ahern, 1999), as discussed below.

6.8.5 Reflexivity

Reflexivity is a process of self-awareness that was developed in the field of phenomenology, and is now widely used in many flexible study designs in an attempt to demonstrate the trustworthiness of the research (Jootun et al., 2009). Reflexivity is discussed in depth in nursing and midwifery literature, where it is

often the case that the researcher is also the practitioner and may have some personal involvement with the participants. In the case of this study, although none of the participating mothers were on my caseload at the time of the study, they were nevertheless known to me, or I knew their current speech and language therapist.

Reflexivity relates to the degree of influence that the researcher brings, either intentionally or unintentionally, to the findings of the study. (Jootun et al., 2009) defined reflexivity as

> *'The continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence, and those of the participants, which can affect the interpretation of responses'* (p. 42)

An attempt to reflect on the process of one's own study, and understand how one's own values and views influenced the findings, adds credibility to the study and should be part of any method of qualitative enquiry (Jootun et al., 2009).

One study, which attempted to understand how students entering the nursing profession learnt how to nurse, found that because the researchers personally knew the lecturers the students were discussing during the study interview, they felt an urge to defend their colleagues when they were being discussed in a negative manner (Jootun & McGhee, 2006). The researchers were able to overcome this by focusing solely on the students' experiences and identifying and acknowledging their own beliefs and separating them from those of the students.

Prior to the start of this study it was acknowledged that it might be possible that during the study mothers may express dissatisfaction with either the therapists involved or with the interventions that they have received. It was therefore

essential, as a researcher and as a practising speech and language therapist, that a concerted effort was made to focus on the mothers' experiences and to identify and acknowledge my own beliefs, preconceptions and assumptions. Indeed, the reflexive researcher must acknowledge that the findings of the study are ultimately the product of the researcher's interpretation of the participants' narrative (Jootun et al., 2009). During this study, in order to try to minimise any ambiguity, the interview questions, although semi-structured, were used as the basis for subsequent interviews, and questions were reframed following each interview, in order to mitigate any misunderstanding that had occurred.

Authors such as Ahern (1999) and Finlay (2003) identify potential areas of researcher bias and suggest strategies to deal with these threats, which Ahern (1999) describes as 'reflexive bracketing'. Bracketing is a way of demonstrating the robustness of the data collection and analysis, and involves the researcher being iterative and reflexive in order to evaluate the effectiveness of the process of study.

For the purpose of this study Ahern's (1999) proposed reflexive strategies were used, and a personal reflexive journal was kept (it has not been possible to include an example of this reflexive journal in this thesis as it was recorded on an NHS laptop specifically encrypted for this study. The way in which it was encrypted did not allow the transfer of any media data onto any other device). Reflexive memos were also written immediately following any interaction with the mother (see appendix 6, p.358). The following procedures were utilised:

- Recording of personal issues when undertaking the study. For example are the 'taken for granted' assumptions associated with the researcher's gender, race, socio-economic status, and the political milieu of the study

recorded? Also a consideration should be made as to where the power is held in relation to the study project, and where the researcher belongs in the power hierarchy.

- A clarification of the researcher's personal value systems and an acknowledgement of areas in which the researcher knows she is subjective.

- A description of areas of potential conflict.

- The identification of any researcher's interests and consideration of the extent to which they are disposed favourably or not towards the project.

- The recognition of feelings that could indicate a lack of neutrality.

- Observation of whether there is anything new or surprising in the data collection or analysis. If not, is this an indication of saturation? Seek out alternative cases.

- When a block occurs during the study process reframe the process.

- When the analysis is completed, a reflection on how the analysis is written up should be carried out and a reflection on whether more quotations are being used from one participant than another.

- An acknowledgement that bias may enter the data collection and analysis process.

It is possible that at any point during the study process a connection may be made between the researcher's behaviour and the underlying motives which will indicate the presence of bias that may be affecting the data collection or analysis. In which case, Ahern (1999) suggests, the researcher has become a reflexive researcher.

6.9 Ethical considerations (and ethical approval)

Applying for and gaining ethical approval prior to any data collection was vital. It not only ensured that the research was carried out in a manner in which any potential harm which would result from the interaction with the participants would be minimised, but also raised awareness regarding how potentially very emotional situations could be dealt with. Request for ethical approval was made to the appropriate NHS National Research Ethics Committee in the autumn of 2008. The application included a copy of the Parenting Stress Index, a copy of the interview schedule, the mother/child interaction coding schedule, consent letter, letter of invitation and patient information sheet. Ethics approval was also sought from the university ethics committee (The Faculty of Health and Social Care Ethics Committee) and Research and Development approval was sought from the local primary care trust (PCT).

Ethics is concerned with the concept of right and wrong behaviour, and in the case of health ethics is underpinned by the principle of beneficence, which requires that evil will be avoided and good will be done, and also the principle of non-maleficence which dictates that research refrains from doing harm.

The key ethical issues in this study were the safeguarding of the mother from emotional harm following a potentially upsetting interview. In order to mitigate this potential harm the following strategies were adhered to: reassurance that she could stop the interview at any stage and that all information was confidential. A discussion was also held with the mother regarding the emotional nature of the topic prior to the interview. I also explained to the mother that I am also a parent of a child with autism and therefore understood her potential difficulty discussing the issues.

In practice it was the case that all but one mother did become upset during the interview and all were given the option of discontinuing the interview; however, none chose to.

Following a rigorous interview with the NHS ethics committee in December 2008, the committee agreed that the proposal fulfilled the conditions for ethics approval subject to a request for further information. The information that was requested was as follows:

- Reimbursement should be offered to parents having to travel into the Child Development Centre.
- Provision should be made for mothers to access a specialist who can be contacted if they became upset or distressed.
- A separate consent form should be provided for the mother to consent for the child participating in the videoed interaction.

All these issues were addressed within the amendment. Permission for a senior clinical psychologist from the PCT to provide support for mothers if necessary was also obtained, although none of the mothers who were upset during the interview accepted the offer of a session with the psychologist.

Ethics approval from the Faculty of Health and Social Care and NHS Research and Development approval were both granted in January 2009.

During the study two minor amendments were applied for to the original NHS ethics committee in February and May 2010. These were granted and were as follows:

In the original proposal the unusual case was to be recruited from the pre-school pathway from a neighbouring locality but still within the same primary care trust. The minor amendment requested that a child from the school-age pathway from the same locality be used.

Permission was sought to use the PSI post-interview in addition to pre-interview.

During the study ethical issues of informed consent were addressed through mothers being provided with an information sheet, and clarification provided during the telephone call and at the start of the interview. All mothers were also asked to sign a consent form. Mothers were notified that they were free to not answer any questions and could stop participating at any time during the study without affecting their rights or receipt of health care. In order to protect the identity of the participants, pseudonyms have been used throughout this study for both the mothers and the children. These pseudonyms are fictitious and are in no way similar to the real names of any participants. All electronic and paper copies of data and personal information were safely stored on password protected computers and in lockable filing cabinets.

6.10 Conclusion

This chapter has given an overview of the naturalistic worldview and case study methodology adopted for this study, and included justification for choosing the case study methodology as well as a definition of the case. The collection of individual data was described. The context of the study and recruitment of the participants has been given. An overview of the analytical framework for *phase*

one as proposed by Miles & Huberman (1994), which was divided into three stages, was presented. The notion of phase two was introduced and finally rigour and ethical considerations were discussed.

In the following chapter the pilot study will be presented. The pilot study was carried out as a full case study in order to prepare and finalise the rationale for data collection for the main study.

CHAPTER SEVEN

THE PILOT STUDY

The previous chapter discussed the methodology and methods used in this study and introduced the analysis plan for phase one of the study.

7.1 Introduction

This chapter introduces the pilot study which was carried out as a full case study prior to any other data collection for the main study. This chapter is divided into two sections:

- The data collection and results

- Reflections and refinements

7.2 Rationale for the pilot study

A pilot case study can be carried out in order to prepare and finalise the rationale for data collection for the main study (Yin, 2003). It assists with regard to the procedures to be followed for both the collection and content of data. Yin (2003) suggests that when deciding upon the pilot case the participant should be amenable and accessible and that the geographical situation should be convenient. This allows the researcher to concentrate on refining data collection plans without concerns such as withdrawal from the research, and lengthy journeys to access participants. In contrast, he also suggests that a pilot case

could represent the most complicated case in order that every possible difficulty may be encountered and dealt with.

For the purpose of this study it was decided that an amenable and accessible participant was particularly desirable due to the sensitive nature of the interview questions, and the necessity to further develop the observation schedule for the mother-child interaction without the risk of withdrawal. The chosen participant had previously expressed an interest in the research and was therefore keen to participate in the study. The family lived within close proximity to the Child Development Centre and therefore there were no difficulties with access or travel.

7.3 Participant and recruitment

Jill, who is aged 49, is married with one child, Alison. She works part-time and is the primary caregiver for Alison. Alison was diagnosed at the age of two years 11 months with autism and an additional learning disability, by which point she was attending a specialist day nursery for children with autism and learning difficulties. Alison has remained in this school placement since her diagnosis. Table (7.1) summarises the demographic information for this case study.

Table (7.1) Demographic characteristics of the mother and child

Demographic characteristics	
Age of mother	49
Race	White British
Relationship status	Married
Other children	No
Employment	Part-time
Prior experience of disability	Yes (minimal)
Age of child at diagnosis	2 years 11 months
Gender	Female
Diagnosis	Autism spectrum disorder
Additional diagnosis	Learning disability
Language level at start of assessment	Non-verbal
Age of child at start of research	65 months

The process of assessment for a diagnosis of an autism spectrum disorder for this family lasted 15 months as the differential diagnosis was questionable at the initial feedback session. During this time Jill and Alison received interventions focused upon helping with interaction, communication and play. The timing of assessment, interventions and diagnosis can be seen in figure (7.1).

The mother and child for the pilot study were selected from the speech and language therapy case load from the participating primary care trust (PCT).

Figure (7.1) Timeline of assessment, diagnosis and interventions
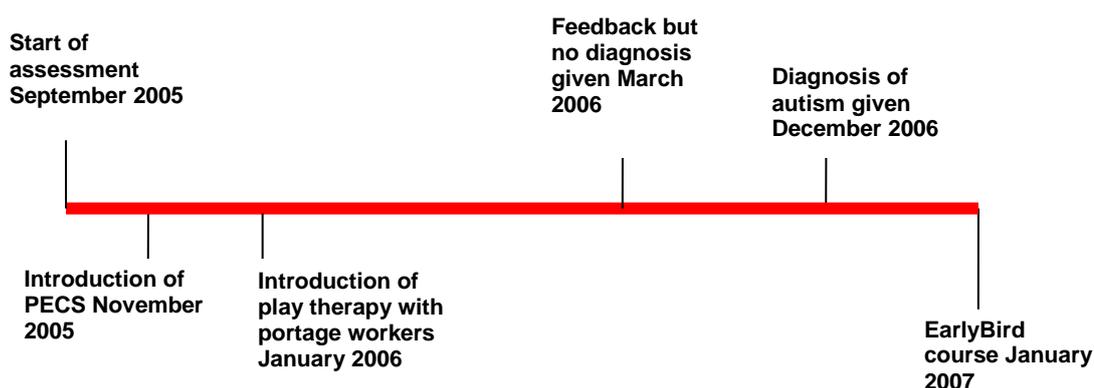
PECS = Picture Exchange Communication System (Bondy & Frost, 1994)

Portage (Shearer & Shearer, 1972)

7.4 Procedure

A full description of the collection and analysis of the qualitative and numerical data and the integration of the two different types of data has already been described (chapter 6.4, p.91). Jill was initially sent the Parenting Stress Index questionnaire (PSI) through the post. This was completed following the interview but before the video of the mother-child interaction. All of the data was collected prior to any analysis, in order that the results from the questionnaires would not influence the interpretation of the observation data which took place immediately following the video.

7.5 Data collection procedures

A detailed description and rationale for using a semi-structured interview, for the mother-child interaction (including coding strategies) and for the PSI (as well as

individual domain descriptions) have already been given in the methods section of this thesis (chapter 6 p. 75), along with support for the validity and reliability of these data collection methods.

7.5.1 The interview

Jill was given the choice of participating in the interview either in her own home or in the Child Development Centre, and she chose her own home as she felt this would help her feel relaxed during the interview. There was a good degree of rapport between Jill and myself during the interview. The interview was twice interrupted by the telephone ringing, and once this happened during a very emotional discussion. The interview lasted two hours and was carried out prior to the completion of the PSI and the mother-child interaction observation.

The interview data was audio-recorded and was transcribed immediately following the interview, resulting in thirty pages of transcript. Analysis of the interview data was carried out using NVivo (QSR International), a computer package to aid qualitative analysis. The transcribed interview data was reduced, coded and sub-themes and themes were developed which are presented in section 7.7, p.141. This data reduction was based on the qualitative data analysis suggested by Miles and Huberman (1994) (chapter 6.6.1.1, p. 103).

The rationale for the choice of the interview questions is already given (table 7.2, p.126); however, as Denzin (1989) suggests, the faulty design of any research tool will distort the final results of the study. Therefore the questions were designed with the intention of exploring, in depth, the relationship in a

subtle manner without making the mother feel uncomfortable due to the bluntness of any questions. The pilot interview questions are detailed in Table (7.2).

Table (7.2) Original interview questions

	Pilot Interview Questions
1.	Can you explain to me in what way you felt that there was something different about your child before they had the assessment? (Additional prompts) Can you explain that further or give me examples?
2.	Can you tell me if you can remember what your attitude was towards disability before you had your child?
3.	Can you explain what your attitude towards disability is now?
4.	Can you explain what it was about your child that worried you more than anything else before the assessment?
5.	Do you feel that interaction with your child was easy before you received the diagnosis? (Additional prompts) Has this changed at any point?
6.	How did their difficulties with communication make you feel? (Additional prompts) Did you feel disappointed?
7.	Can you explain to me whether you think that your child's difficulties affected the way you felt about him / her?
8.	Did you receive any strategies to help with communication that helped you overcome your child's difficulties? (Additional prompts) Can you tell me what they were?
9.	Are there any strategies that you have been given that have made interacting with your child easier?
10.	Can you describe whether these strategies had any effect on how you felt about your child?
11.	Can you explain whether there was anything about the way that the professionals who were carrying out the assessment or the therapy behaved that made things either easier or more difficult?
12.	Was there anything during the period of assessment that you think helped you to come to terms with the diagnosis better?

7.5.2 The mother-child interaction observation

The pilot video of the mother-child interaction was an attempt to ensure that the operational and strategic measures were in place, and to have the opportunity to systematically rate behaviours observed between the mother and her child. This would enable me to refine the observation and gain some understanding of this complex relationship which was interpreted from these observed behaviours. In order to accomplish this, it was essential to observe not only the mother's behaviours but also the child's behaviours, and whether these behaviours had an effect upon the mother. The method of observation and selection of behaviours to be analysed was based upon research carried out by Lemanek, Stone, & Fishel (1993), Doussard-Roosevelt et.al. (2003), Watson (1998), Horowitz et.al. (2005) (see chapter 6.4.2, p.93)

Jill and Alison were asked to attend their local Child Development Centre which they had both attended in the past. A selection of toys, which had been previously identified by the researcher as being suitable for encouraging interaction, were placed on a low table in the middle of the playroom (list of toys in appendix 15, p.378). There were also several chairs around the table of differing sizes for Jill and Alison.

Permission was again sought to video the session and it was explained that the session would last approximately 30 minutes. This allowed for 20 minutes of video and 10 minutes of feedback following the video. Jill was asked to play with Alison in exactly the same way that she would at home.

It had been hoped that it would be possible to video the interaction without the researcher being in the room; however, this was not possible as the room with the permanent video equipment was not available at the last minute.

Jill and Alison were videoed interacting for 20 minutes.

7.5.2.1 Coding of the observation data

The coding of the mother-child behaviours was carried out immediately following the video of the interaction. The video was transferred onto the encrypted laptop used for this study, and a time code was added to the video in order to facilitate coding and analysis. The analysis commenced after eight minutes of video which enabled the mother and child to settle into the interaction prior to the analysis. The following four minutes of video were analysed, which was felt to be a sufficient period to carry out detailed analysis of the behaviours of the dyad. Neither the verbal interactions nor the vocalisations were transcribed but were analysed as part of the coding. The video was viewed four times, and during each separate observation the mother's and child's behaviours were coded and the time spent in shared attention was recorded. Results from the coding of the interaction gave an objective measure of the mother's positive, neutral and negative behaviours in relation to her child's behaviours. The video was then viewed a final time and any other observations made by the researcher were recorded. These included the researcher's impression of the mother-child relationship and the reciprocity of the relationship.

7.5.3 The Parenting Stress Index (PSI) (Abidin, 1995)

The PSI was completed by Jill following the semi-structured interview. When analysing the results from the questionnaire, it was evident that she had based

her answers upon her emotions during the time prior to the successful implementation of any interventions and prior to the diagnosis (early emotions), as they did not reflect her present emotions (later emotions) that she described during the interview. Therefore, following permission from the NHS ethics committee, Jill was asked to complete a further PSI but to base her answers upon her present emotions (later emotions). (The justification for this is discussed in section 7.11.3. p.160).

7.6 Results from the individual sources of data

The following section gives a detailed interpretation of the results from the mother-child interaction and the PSI. This is followed by a conceptually clustered matrix where these results, in addition to the results from the interview data, are merged. Finally each theme, which was developed from the merging of the data, is presented as a narrative and quotations are used to illustrate the themes.

7.6.1 Results of the mother-child interaction

The development of the coding of the mother-child interaction has previously been discussed in chapter (6.4.2, p.93) with detailed definitions of maternal and child behaviours in appendix 6 and appendix 7 (p.358). The analysis of the mother-child interactions aims to make a judgement regarding the mother's relationship with her child based upon observations of the mother's affect, her positive, neutral and negative behaviours in response to her child's behaviour,

and the total time spent in sharing attention. This data was analysed using descriptive statistics and was then included in the conceptually clustered matrix.

The percentage of very positive and positive behaviours exhibited by Jill made up 83% of her behaviours whereas Alison's behaviours were 80% neutral and 20% negative. The dyad spent 95% of the time sharing attention. Figure (7.2) provides an overview of the percentage of positive, neutral and negative behaviours observed in both the mother and the child.

My observations and interpretations of the relationship are described in the mother-child interaction section of the conceptually clustered matrix.

Figure (7.2) Percentage of positive, neutral and negative behaviours
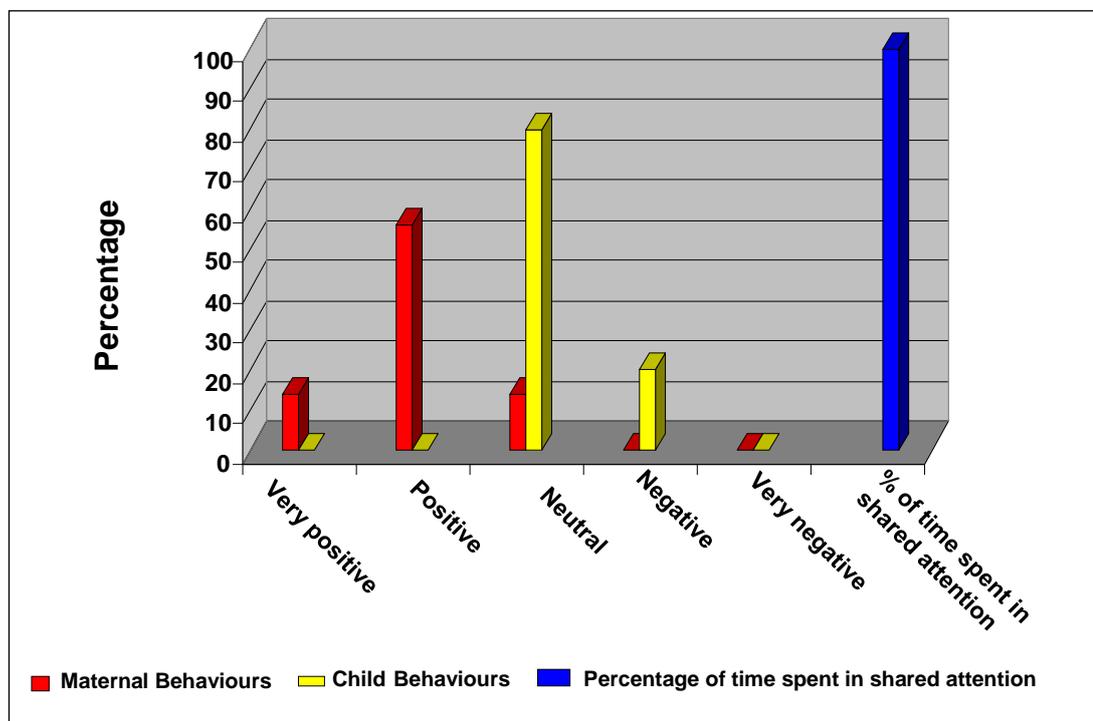
7.6.2 Results from the PSI

The following section presents the results from the PSI.

7.6.2.1 PSI maternal domain scores

The maternal 'early emotions' domain subscales were between the 1st and the 99th percentile with **competence**, **depression** and **spouse** all scoring between the 93rd and 99th percentile, whereas the 'later emotions' subscales ranged between <1st percentile and the 95th percentile. The parent score was skewed slightly by the **health** score which was 19 (95th percentile). This was due to the fact that Jill had had an unrelated health problem just prior to completing the questionnaire. These results can be seen in figure (7.3).

Figure (7.3) PSI maternal domains
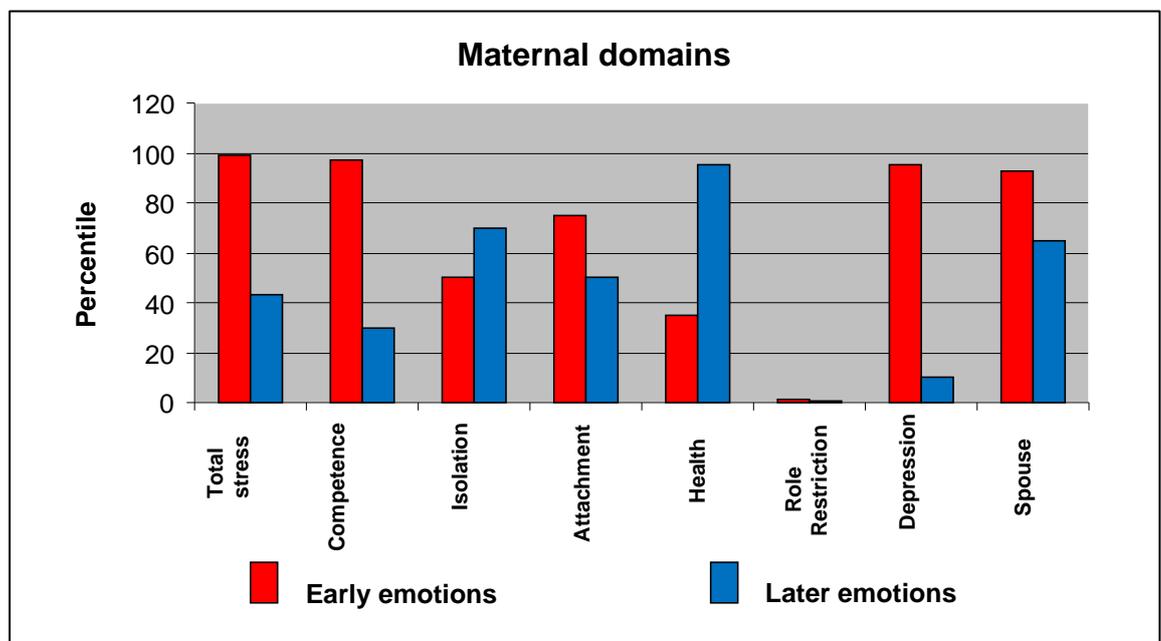
PSI scores between the 15th and 80th percentiles are considered to be within the normal range. Scores above the 80th percentile are considered high and deemed to be indicative of dysfunction.

7.6.2.2 PSI child domain scores

The 'early emotions' child domain subscales were all between the 95th and the 100th percentile. However, the results from the 'later emotions' were very different with scores ranging from the 1st percentile to the 90th. The subscales which attained the highest scores in the first PSI were **adaptability** (100th percentile), **distractibility** (99th percentile), **reinforces parent** (99th percentile), **acceptability** (99th percentile), **demandingness** (96th percentile), and **mood** (96th percentile). However, the 'later emotions' domain scores were: **adaptability** (80th percentile), **distractibility** (65th percentile), **reinforces parent** (1st percentile), **acceptability** (80th percentile), **demandingness** (70th percentile) and **mood** (90th percentile).

The early and later child domain scores can be seen in figure (7.4)

Figure (7.4) PSI child domains
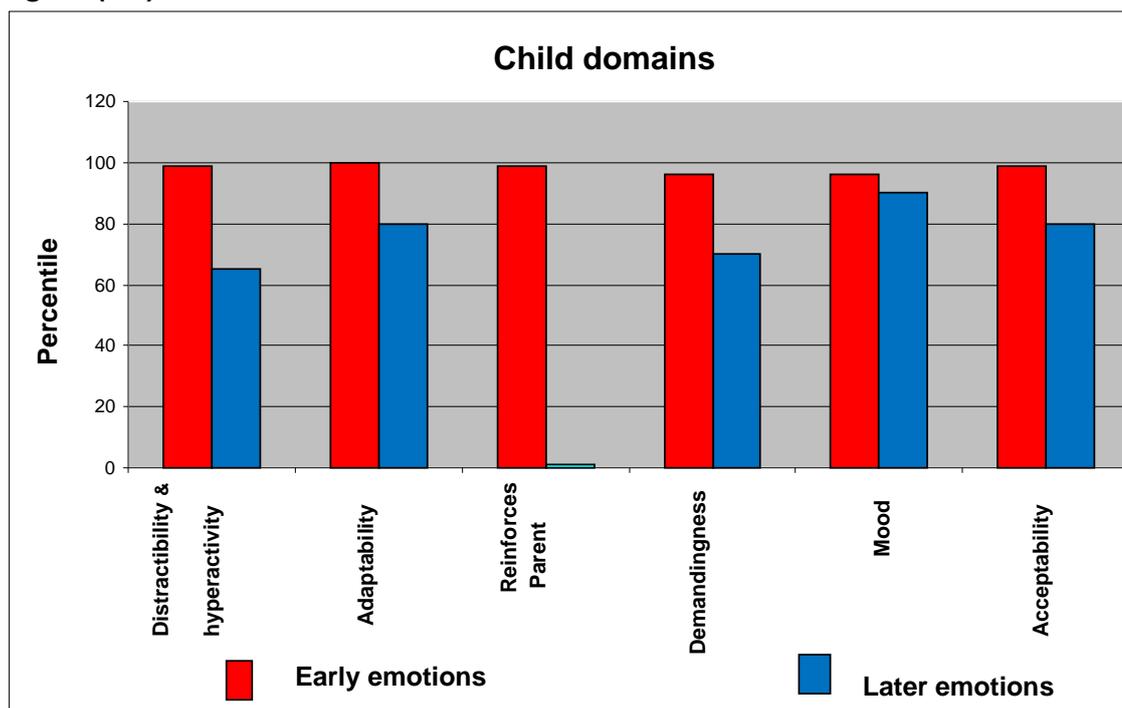
The total stress score for the 'early emotions' period was 320 (99th percentile). The child domain was 170 (above 99th percentile) and the parent domain was 150 (87th percentile). The total stress for the 'later emotions' period was 215 (43rd percentile), with the child domain score being 107 (68th percentile) and the parent domain score being 108 (27th percentile).

The parent and child scores will be discussed separately. Figure (7.5) depicts the total stress score for both the early and later emotions.

Figure (7.5) PSI total stress, child and parent domains
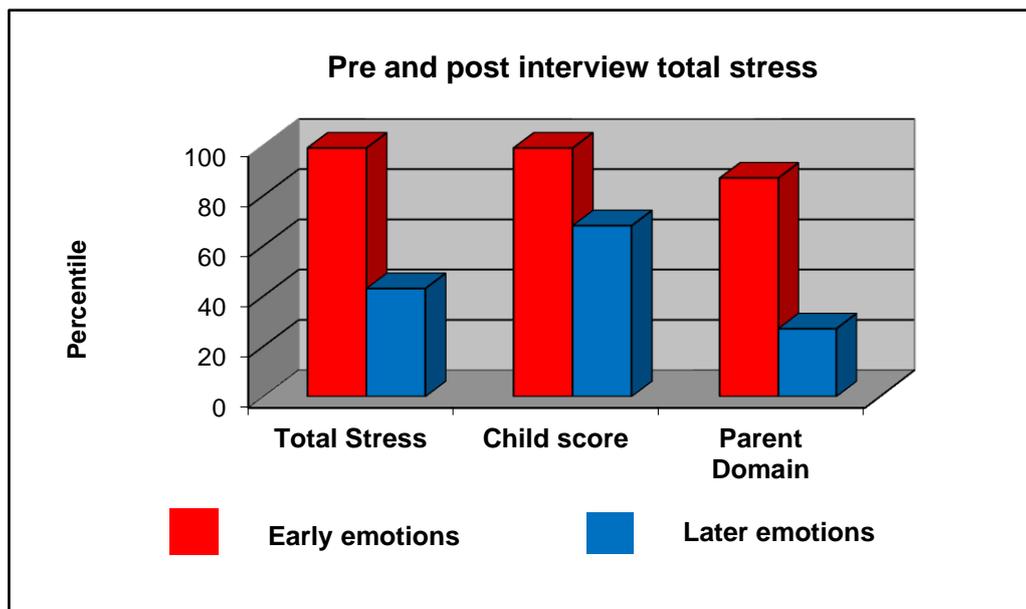
7.6.3 Overall results from the PSI

The PSI identified areas of stress emanating from the mother-child relationship, and in particular Jill's perceptions of how Alison affected the relationship. During the early emotions period and prior to the successful use of strategies, the principal area of stress, as perceived by Jill, was Alison's difficulties with **adaptability, distractibility** and **acceptability**. These difficulties demonstrate

Alison's inability to adapt to her social environment. The **reinforces parent** subscale referred to how Alison's behaviour reinforced Jill's negative feelings as a mother. Abidin (1995) argues that a parent may feel that their child is not a source of positive reinforcement, and it appeared that the emotional and behavioural characteristics of Alison did not match the expectations that Jill had as a mother. Abidin (1995) also suggests that the **reinforces parent** is highest amongst parents whose interactions with their child fail to produce good feelings about themselves, and may result in parents feeling rejected by their child. Jill expressed significant difficulties in the area of **competence** which Mouton and Tuma (1988) suggest is found in parents who do not find the role of parenting reinforcing, and who experience a sense of 'this is more than I bargained for'. These difficulties resulted in Jill scoring on the 99th percentile on the **depression** subscale which Webster-Stratton (1998) suggests is indicative of significant depression.

The 'later emotions' PSI revealed a very different picture. **Adaptability**, **acceptability** and **distractibility** all fell within the 70th to 80th percentile. However **reinforces parent** was now reported to be at the 1st percentile suggesting that Jill now found Alison to be a source of positive reinforcement, and subsequently Jill's feelings of **competence** were significantly improved. Jill no longer reported being depressed although the subscale in the child domain **mood**, which is described as being high in children whose affective functioning shows evidence of dysfunction (Loyd & Abidin, 1985), remained at the 90th percentile. It is possible therefore that despite Jill still reporting that Alison's mood was difficult, the **reinforces parent** domain was significantly improved, therefore affecting **competence** which in turn reduced her feeling of depression.

The following section presents the conceptually clustered matrix (table 7.3) followed by an association network (figure 7.6) which depicts the dynamics of the relationship. Finally a narrative of the themes is presented.

Table (7.3) Conceptually clustered matrix: Themes emerging from interview and numerical data

Qualitative themes	Interview	Parenting Stress Index	Mother-child interaction
Mother's affect	**Early emotions** Sadness: 'it was an awful time, it was an awful time because there was denial, there was deep sadness (crying) it's me because I felt such a failure, I felt like I'd failed' Rejection: 'I thought my God she just seems never to cry or, you know and I was just trying to play with her you know and tickle her and she just sort of would turn away, she'd turn away from me' Guilt: 'I felt guilty for not being a proper mother' Anger: 'I was really angry actually at her. That was wrong you know to be angry at her it wasn't her fault, but I was angry at her' **Later emotions** Changes in affect: 'I've put it on the Facebook. I've put it on Facebook with me, you know support autism and she's on there. she is on Facebook with me. Me and her together that's our picture. I'm so proud of her, you know, I really am'	**Early emotions** (Depression/ mood) High (99th percentile) Mother scored over 85th percentile on 8 of the 9 questions which focused on guilt and sadness. Guilt: 'When I think about the kind of parent I am, I often feel guilty or bad about myself' Sadness: 'After my child had been home from hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected' **Later emotions** (Depression) Low (10th percentile) Mother's affect now much improved. Expressing greater resource and much less guilt.	Very positive: Mother's mood was extremely warm and enthusiastic during interaction. She appeared to enjoy the interaction with her daughter.
Relationships with others	**Early emotions** Not being believed: 'everybody wouldn't believe it. They couldn't see what I was seeing , everybody. And that was including my family, and they and even close friends, very close friends' Jealousy: 'Jealous, I was very very jealous of other mothers'		
The diagnostic process	Time: 'Time it wasn't rushed. It was the being I don't know. You just seem to get the timing just right. It was just right, when Alison was starting to do a lot more. You know, when she was. She had the PECS on the go, she was in nursery, everything seemed to be sort of like slotting into place and then it was never, it was never rushed. You can't be rushed into something like that' Someone else to take responsibility: 'I think that once we started on that pathway. I felt, like almost as if arms had embraced me and they were there to help me' Help for me as well as my daughter: 'I knew that there is a support network, a support network there for me as well, and it was that support I hadn't had. I just felt well relief and I felt relieved that I was in the right place', 'We had a pathway that was leading us out of this wilderness. We had it' Strategies in place before the diagnosis: 'I think if we'd just been given		

	that diagnosis of autism without knowing about the nursery, without knowing what we can do, and where we are going, and to be given a diagnosis, not knowing where you are going with that diagnosis, not knowing what you're going to do with that child, that would have been dreadful. If you know what you are going to do made a big difference'		
Relationship with partner	**Early emotions** Partner not on board: 'No he wasn't on board he didn't want to think anything was wrong' Not being believed: 'I would say to him well why isn't she looking at me, she's not looking at me, and he used to say oh you're imagining things, you're imagining things' Mother wanted to be most important person in child's life: 'I did completely and utterly reproached myself and I thought, well, you don't even know how to play with her. I just really punished myself. I did cos I thought it was me cos my husband plays with her, why can't I', Anger towards partner: 'I felt very angry towards my husband. I never said one word to him and I thought it's got to be his fault' **Later emotions** Father began to encourage interaction: 'She would come to me, and that was encouraged by my husband very much encouraged by him.'	**Early emotions** (Spouse) High (92nd percentile) Mother reported feeling that since the birth of her child there had been difficulties in their relationship and with her relationship with his family. **Later emotions** (Spouse) Moderate (65th percentile) Following diagnosis the mother reported fewer difficulties with their relationship; however, she still reported difficulties in finding time for each other.	
Competence as a mother	**Early emotions** Feelings of lack of competence: 'Well I mean it was me, cos she, when I was feeding her she wouldn't look at me, no eye contact, it was very difficult' Mother blaming herself: 'I did feel that there was the stigma a huge stigma, and I didn't know if it was my making or. I didn't want anyone to know about her, I didn't.' Didn't feel like a proper mum: 'there was a detachment, almost. There was a detachment, and I didn't feel like a proper mum' **Later emotions** Increasing competence: 'and suddenly this PECS came in and we knew, and then eventually we got to grips with it, and it was… It was marvellous, because she could give me a sentence about what she wanted and she would come to me. And she would come to me' Feeling like a proper mum: 'It made me feel that she, you know, she'd seen me that I was here as well'	**Early emotions** (Competence) High (97th percentile) During the assessment period the mother had significant doubts about her ability and found the task of being a parent harder than she had expected, and there was a lack of enjoyment, all of which led to her lacking in confidence. She did however feel that she was a very good parent. 'Being a parent is harder than I thought it would be' **Later emotions** (Competence) Moderate (30th percentile) Following diagnosis she still felt that being a parent was harder than she had expected but not to the same degree. She described now feeling that she was capable and on top of things. Her enjoyment of being a parent also increased. 'I feel capable and on top of things when I am caring for my child'	Positive Visual contact, language and non-verbal clues and flexibility were all used in order to support her daughter's difficulties with communication and interaction. This was the case despite the fact that her daughter's behaviours were in the main neutral or negative. Therefore she attempted to maintain synchronicity.

| **Attachment** | **Early emotions**
Effect of significant difficulties with communication and interaction: 'she's not communicating and I'm quite frankly going potty here. I am, I was going ballistic because she wasn't speaking to me. She wasn't looking at me she was. I didn't know what she wanted she didn't know what I wanted'
Mother unsure of daughter's and own feelings: 'there was a detachment, almost. There was a detachment, and I didn't feel like a proper mum. I didn't feel like I knew I loved her I did love her but I didn't think she loved me', 'that was another hard one, because I felt I was betraying her. This huge betrayal, and I did, I thought I knew I loved her. But I didn't like her'
Feelings of rejection reinforced mother's feelings of failure as a mother: 'Well I mean it was me, cos she, when I was feeding her she wouldn't look at me, no eye contact, it was very difficult'
Disappointment, resentment and anger: 'the fact that I think you can only begin to understand when a child that you've wanted so much does not interact with you the way you thought she would then that is heart-breaking it is heart-breaking and I was angry'

Later emotions
Increased communication broke down barriers: 'the PECS it was, because she was bringing it to me. She was bringing the sentences to me, and she was asking me. She was interacting with me, rather than with my husband', 'It was just a wonderment. It really was. It was like, like I had my daughter I had her you know, because before she just didn't communicate with me. She didn't, and to me, that was the first time when she started bringing me those sentence strips', 'eventually, when she started communicating and she would come and put it on me and it was the closeness it just brought us together. It was definitely with me'
Becoming a proper mum: 'It made me feel that my daughter, you know, she'd seen me that I was here as well. You know it wasn't just about dad you know, and her grandfather and grandmother. I was here as well, you know, and that made me feel like a mum' | **Early emotions**
(Attachment) Moderate (75th percentile)
Although the scores were within the moderate score they were nevertheless towards the upper end. There were difficulties in understanding what her daughter wants.

(Reinforces parent) High (99+ percentile)
Expression of feelings that her child did not want to be with her. 'sometimes I feel my child doesn't like me and doesn't want to be close to me'
Later emotions
(Attachment) Moderate (50th percentile)
It was apparent that the mother now had a better understanding of what her daughter wanted which increased her feelings of attachment.

(Reinforces parent) Low (1st percentile)
Significant change in mother's perceptions about her daughter wanting to interact with her. | Positive attachment
The mother's affect and time spent in shared attention gave an impression of the mother's positive attachment.

Positive reciprocity
Despite the child's behaviours being 80% neutral and 20% negative, the mother was able to achieve mainly positive scores for her behaviour, and shared attention was maintained for 100% of the interaction. |

| The effects of interventions | Understanding the autism: 'It really did help me to understand Alison. I didn't feel I ever understood her, you know really until the EarlyBird course that you know, I needed to understand why she was like that why she would do these things'

Realisation that mother had to change her own behaviour: 'it was one of them difficult periods where I think, I think we thought it was all just going to land and almost all be miraculously okay', 'It's really changed me, you know, I do things that I thought I would never do you know outside of the house, anything to interact with her. You know to gain that closeness that we have got now that you know, that's really unbelievable from me'

Getting down to her level: 'I know that's how we got to her, along with the PECS I know it was with games, game playing and ehm getting inside her, getting inside her head and getting down to her level'

Learning to communicate: 'I know I know, deep in my heart that if we hadn't had that PECS to begin with, that that communication...... it would be stilted it wasn't moving anywhere. It wasn't going anywhere, even with my husband. We still would have the finger dragging and pointing you know, which wasn't really true, you know interaction. True communication and understanding is what we wanted'

Increase in interaction: 'she had to bring me that sentence strip, and actually interact with me if she wanted something. So in that way, it broke down barriers with me. It broke down barriers' | | |

Labels = themes that emerged from coding interview data

Quotations = direct quotations from participant (names have been replaced by neutral labels)

Short summary phrases = used to explain or qualify a rating

Ratings = these are taken directly from the quantitative analysis of the quasi-experimental data:

- High, moderate, low for the PSI
- Very positive, positive, neutral, negative, very negative for the mother-child interaction

Figure (7.6) Association network for the pilot study

140
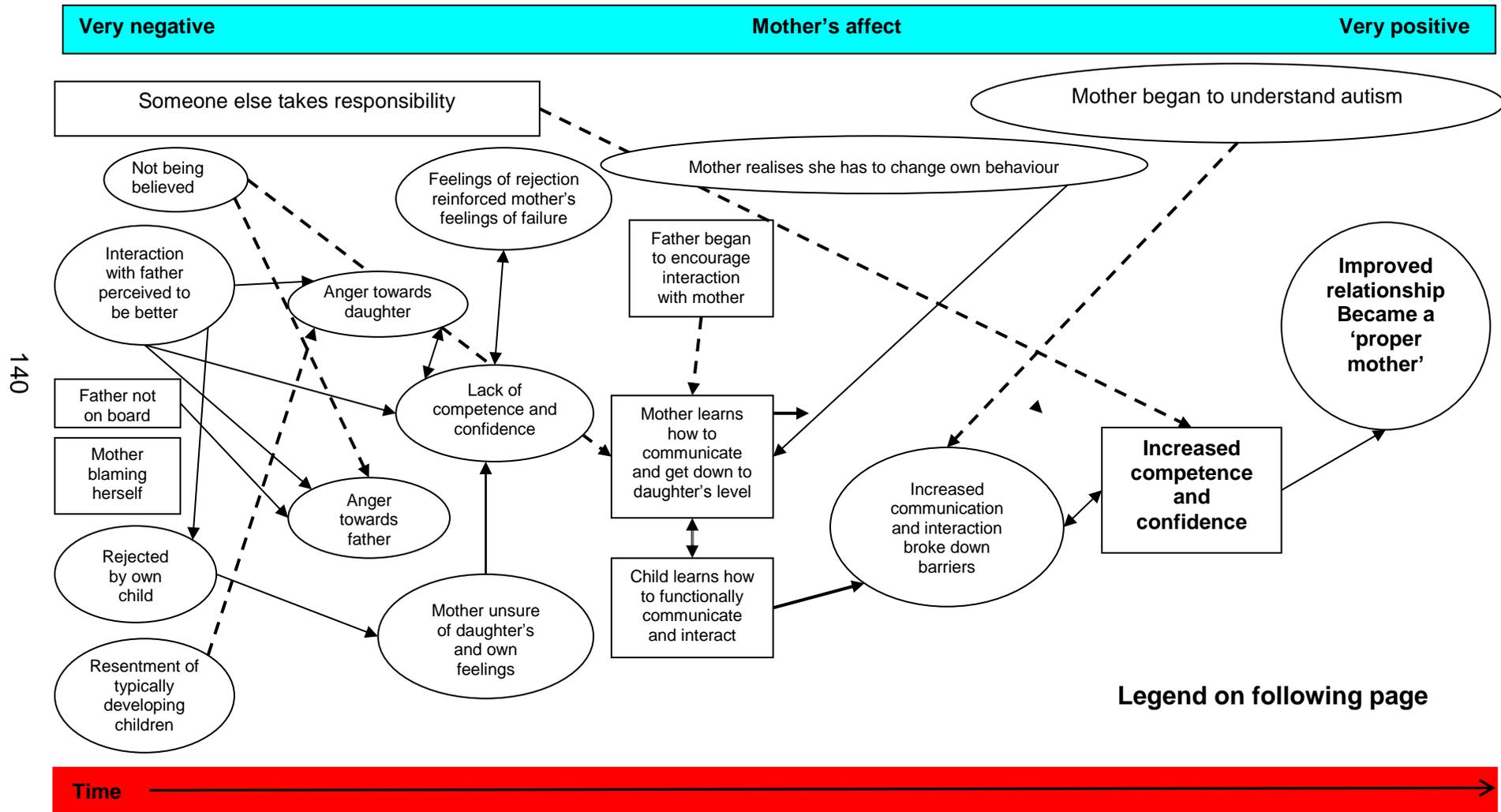
<u>Legend</u>

| Boxes | Are events |
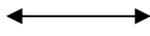
(Bubbles)   Are states

◄――――► Reciprocal influence
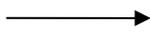
――――► Strong influence
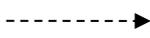
- - - - - -► Weak influence

Note: not all of the boxes and bubbles are connected, as certain states and events occurred independently of each other.

7.7 Overall themes from all data

The following seven themes were generated from the overall analysis of the interview and numerical data.

Theme 1: Mother's affect

Jill talked extensively about her negative emotions during the period of assessment and prior to embracing the therapy strategies. She described feeling rejected by her child which led to anger and resentment, which then resulted in her feeling guilty for having these negative feelings. This was reflected in her depression score (99th percentile) where she scored high on her feelings of guilt and sadness. For example she said

> *'I was so sad. I was so desperately sad, and I didn't want to be that way. I wanted to be happy and you know just I wanted to be able to play with her and get her to play with me'* (NVivo line number 944)

Following the implementation and utilisation of the communication strategies Jill reported a dramatic change in her affect (10th percentile), and she described feeling happy when her daughter began to interact with her. She also began to see how disability had affected other children and she felt lucky that her daughter had not been affected in the same way.

> *'I realise that if you just go to the nursery you see how bad some of the other children are, and you know how lucky we are to have Alison how lucky, you know, because gosh a child without any disabilities you know, anything could happen to the child, you know we are not all invincible you know, anything could happen to each and every one of us and you've just got to make the most of it'* (NVivo line number 714)

She attributed her change in mood to her daughter being able to interact with her in a way that she had never before.

> *'It was just a wonderment. It really was. It was like, like I had my daughter I had her you know, because before she just didn't communicate with me. She didn't, and to me, that was the first time when she started bringing me those sentence strips'* (NVivo line number 457)

(<u>Very positive _(mother-child interaction)</u>) The positive change in her affect was reflected in her resourcefulness observed during her interaction with Alison, where she was extremely warm and showed definite enthusiasm and enjoyment during the interaction. This was despite the fact that Alison showed indifference towards Jill and was more focused upon the activity.

Theme 2: Relationships with others

Jill described feeling jealous of other mothers and their relationships with their children. Watching these interactions reinforced her feelings of failure.

> *'I felt like I'd failed, you know all my friends had children; nobody seemed you know to have anything wrong with their children'* (NVivo line number 276)

> *'Jealous, I was very very jealous of other mothers'* (NVivo line number 1034)

These feelings of jealousy and resentment were further reinforced by not being believed by her friends and family, which she found patronising, and also by the fact that she perceived the interaction between Alison and other family members to be better than it was with her.

These feelings of jealousy and of not being believed led to Jill concealing the fact that there were any difficulties from anyone outside the immediate family, but this put a huge strain on her and on her relationships with others.

> *'I kept a lot of it to myself, I didn't discuss it with anyone outside of the family and that was a huge strain in work, especially in work, everybody's talking about their children and I think at one point I was making things up you know, I thought just to shut them up really, and say oh she's doing this and she's doing this and she's fine you know she's great. It was a huge strain.'* (NVivo line number 281)

Theme 3: The diagnostic process

Once the assessment started, Jill felt a huge relief that someone else was taking some responsibility for the burden that she had been feeling, and that she was able to hand over that burden to the professionals.

> *'I think that once we started on that pathway. I felt, like almost as if arms had embraced me* (crying) *and they were there to help me'* (NVivo line number 340)

She also viewed the professionals being there as a support to her as well as assessing her daughter, support which she felt no one had been able to give her prior to this assessment.

'I knew that there was a support network, a support network there for me as well, and it was that support I hadn't had. I just felt well relief and I felt relieved that I was in the right place' (NVivo line number 351)

The welcome that she was initially given helped her to feel that the assessment was partly about her as well as Alison, although she did describe feelings of intrusion initially as professionals would come to her home and tell her how to interact with her daughter.

'The only thing was at first I didn't like the intrusion. I didn't like the intrusion cos I felt like again, almost strained. Just being sectioned out. Other mothers can just get on with their lives. They can just do what they want with their children and never have any of these people coming into their house. You know, the professionals coming in and telling me to do this that and the other or advising me to do this and that' (NVivo line number 919)

Once Jill realised that their relationship would benefit from her changing her own behaviours, she then began to welcome the professionals' advice and looked forward to their visits.

Jill described the most important factors of the diagnostic process as being the time that it took, and the fact that by the time the diagnosis was given there were already several successful strategies in place. She stated that if the diagnosis had been given prior to these strategies being used successfully she would have found it extremely difficult to accept the diagnosis.

'Time it wasn't rushed. It was the being I don't know, they just seem to get the timing just right. It was just right, when Alison was starting to do a lot more. You know, when she was, she had the PECS on the go, she was in nursery, everything seemed to be sort of like slotting into place and then it was never, it was never rushed. You can't be rushed into something like that you can't be given such a blow. It has to be an easy one and that was an easy one for us. It would have been severe to have gone, yes we've had a good look at her over a couple of months, and yes, she is autistic that would have just devastated us, because everything wasn't in place. It would have been too quick, and we needed to know it was thorough, and you know the things were in place' (NVivo line number 968)

Part of the reason that Jill felt supported during this journey was the fact that she and her husband had a clear pathway where they knew what each next step was to be and that the professionals communicated this with her.

> *'We had a pathway that was leading us out of this wilderness. We had it'* (NVivo line number 887)

Theme 4: Relationship with partner

Jill described how she felt that her husband did not believe her when she expressed concerns about Alison and how he would deny that there was anything wrong with her. He would accuse her of imagining things which eventually led to her keeping things from him. She described a feeling of despair as friends, family, her partner and some professionals refused to believe her that there was something wrong with her daughter. Jill's **spouse** score in the PSI was on the (92nd percentile), which describes not having had as much help and support as she had expected. The refusal of Jill's husband and other friends and family members to acknowledge that there were difficulties resulted in Jill feeling that she was imagining these difficulties, which in turn confirmed her feeling of lack of competence as a mother.

> *'I was patronised, she's only young give her time, she will be all right and then I got back home and it seemed like I was getting it everywhere. You know I thought it was me, it's me I'm imagining all of this*' (NVivo line number 258)

Jill talked a lot about how Alison would interact with her father and not with her. She talked about this in a way that suggested she seemed to resent his ability to interact with her, and felt that her daughter almost preferred her father and Jill was being excluded. Once the interaction between Jill and Alison did improve

she was keen for it to be just between her and her daughter and almost wanted to exclude the father.

> *'I suddenly realised, it was a sudden realisation that she wants to be near me now. You know, and she didn't really want to be near her Dad'* (NVivo line number 601)
>
> Q. What was it about the play that made you happy that made the difference?
>
> *'The communication afterwards that she would want to continue to play those games. And she would seek out the person that knew how to play that game and if I was privy to that she knew it was me and not her Dad'* (NVivo line number 960)

The resentment that she felt towards her husband resulted in her feeling very angry towards him, and she described how she wondered whether it was his fault that they had had a disabled child:

> *'I felt very angry towards him. I never said one word to him and I thought it's got to be his fault. There is nobody in my family'* (NVivo line number 1012)

Following the successful introduction and use of the communication and interaction strategies, she talked about how eventually the father encouraged Alison to interact with her and how she could not believe that she had ever blamed him:

> *'She would come to me, and that was encouraged by my husband, very much encouraged by him. No no your mum take it to mummy and she'd bring it to me when she had to and she'd come over and communicate with me and it was marvellous it was like a revelation almost'* (NVivo line number 420)

Theme 5: Competence as a mother

The concept and desire to be a competent mother was of constant concern to Jill. On several occasions she described her feelings of not being a proper mother. She ascribed her feelings of not being a proper mother to her own

failings, such as not being the kind of person who is constantly offering physical

contact and not being able to interact with her own daughter:

> *'I mean I felt in a way it was my fault because I'm not the most touchy or feely of people. And I thought, well, she's picked up on that. She has she's picked up on it because that's why she's not like that with Ian'* (NVivo line number 516)

> *'I did completely and utterly reproached myself and I thought, well, you don't even know how to play with her. I just really punished myself'* (NVivo line number 519)

Alison's difficulties with interaction and communication appeared to reinforce

Jill's feeling of not being a competent mother. She felt that if she were able to

interact with her daughter and if her daughter interacted with her then she would

be a proper mother. This feeling of lack of competence was also reflected in her

competence score on the PSI (97th percentile), where she described the task of

being a mother as harder than she had expected and she experienced a lack of

enjoyment in parenting.

Once Jill realised that her own behaviours had to change in order to support her

daughter and she started to use the strategies to increase Alison's interaction

and communication skills, she started to feel more competent. It appears,

however, that in order to feel like a proper mother her daughter had to choose

to come to her and not to anyone else:

> *'It made me feel that Alison, you know, she'd seen me that I was here as well. You know it wasn't just about dad you know, and her grandfather and grandmother. I was here as well, you know, and that made me feel like a mum'* (NVivo line number 450)

There appears to have been a realisation that she was able to affect the

interaction that she and Alison experienced:

> *'It's really changed me, you know, I do things that I thought I would never do you know outside of the house, anything to interact with*

Alison. You know to gain that closeness that we have got now that you know, that's really unbelievable from me' (NVivo line number 533)

(Positive (mother-child interaction)) Jill's competence was observed during the mother-child interaction, where she used positive strategies including maintaining visual contact, appropriate use of verbal and non-verbal communications and flexibility in following her child's lead in order to gain and maintain her attention. These strategies were used despite the fact that Alison's visual contact and interactions were mainly neutral or negative during the interaction.

Theme 6: The effects of interventions

Following the initial introduction of PECS and play therapy Jill talked about having the expectation that Alison would start using the strategies herself without the input of her parents:

> '*Do you know, it was one of them difficult periods where I think, I think we thought it was all just going to land and almost all be miraculously okay. You know, and she is going to start putting these things on the sentence strip and she didn't she didn't and it wasn't her fault. It was us because we were lazy we were and you'd given us the tools and we just left, left them there and hoped that she would just sort of you know do it herself'* (NVivo line number 406)

She then had this sudden realisation that Alison was not going to develop the communication and interaction skills on her own, and that if she did not change her own behaviour then Alison's behaviour would not change:

> '*And then I suddenly realised that this was ehm a method of communication that I need. She has to have it because she's not communicating and I'm quite frankly going potty here. I am, I was going ballistic because she wasn't speaking to me'* (NVivo line number 414)

> '*All things that you take for granted, with a child that doesn't have difficulties that we had to do that we had to learn. You know so*

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much and well it was difficult it was difficult because we didn't get our finger out soon enough' (NVivo line number 427)

Jill not only realised that she had to change her own behaviour but also that she had to begin to understand how her daughter thought and how that affected her behaviour. She realised she had to get down to Alison's level in order for things to change:

> *'I know that's how we got to her, along with the PECS I know it was with games game playing and ehm getting inside her getting inside her head and getting down to her level'* (NVivo line number 531)

This was further enhanced following her attendance at the EarlyBird course, where she talked about not truly having understood Alison before then and realising that her difficulties with interaction and communication were not intentional:

> *'It really did help me to understand Alison. I didn't feel I ever understood her, you know really until the EarlyBird course that you know, I needed to understand why she was like that, why she would do these things. And once you start to understand that she is not doing it deliberately, she can't help it'* (NVivo line number 1020)

When Alison did start to communicate and interact with Jill she talked about how it brought them closer together. She talked about how she did not know how to reach her daughter before she had the PECS and the play therapy:

> *'The eye contact was there and so I would bring up the strip, and I'd look at her and she would have to look at me and then you know, then she came out'* (NVivo line number 460)

> *'Eventually, when she started talking with the PECS and she would come and put it on me and it was the closeness it just brought us together. It was definitely with me'* (NVivo line number 462)

Theme 7: Attachment

Jill described in detail her feelings of disappointment, resentment and anger which were all directed at Alison. She could not understand why the child that she had so desperately wanted chose not to interact or communicate with her. These emotions appear to be related to Alison's difficulties with understanding, communication and interaction specifically with Jill. These difficulties had a profound effect on Jill who described becoming a child herself. Because Alison was choosing not to communicate with Jill, as she perceived was the case, she herself decided not to communicate with Alison:

> *'I thought why don't you talk to me it was almost like Hilary I was the child as well, you know, if you don't talk to me I won't to talk to you cos I didn't have that method in place. The ability really to understand that you know Alison needs, needed me because she had this disability you know I didn't want to see it. I didn't want to accept it I just wanted someone to miraculously replace her to take her away. Just to give her that ability to communicate and understand'* (NVivo line number 693)

These feelings of rejection and sadness appear to have reinforced Jill's feelings of failure as a mother:

> *'It was an awful time, it was an awful time because there was ehm denial, there was deep sadness it's me because I felt such a failure, I felt like I'd failed'* (NVivo line number 274)

Before therapy Jill's **attachment** score on the PSI was at the upper end of moderate (75th percentile), where she scored highly on statements such as experiencing difficulties in understanding what her daughter wanted. The **reinforces parent** score on the child domain was high (99th+ percentile), where she expressed feeling unloved and disliked by her daughter. This was also reflected in the interview:

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> *'There was a detachment, almost. There was a detachment, and I didn't feel like a proper mum. I didn't feel like I knew I loved her I did love her but I didn't think she loved me'* (NVivo line number 465)

Following therapy the increase in Alison's communication and interaction skills made Jill feel differently towards her daughter. Because she felt that Alison was now making an effort to communicate and interact with her, this resulted in Jill feeling closer to Alison and gave her the confidence to be a 'proper mum':

> Q. Did you feel that PECS then made a difference to the connection, and how you felt about Alison?
>
> *'Yes, yes it did, because I didn't know how to get to her, I didn't know how to reach her and this was like, you know I'd been given this tool where Alison when nobody else was here she had to come to me'* (NVivo line number 474)
>
> *'It was just a wonderment. It really was. It was like, like I had my daughter I had her you know, because before she just didn't communicate with me. She didn't, and to me, that was the first time when she started bringing me those sentence strips'* (NVivo line number 457)

Again this is reflected in her PSI scores where her **attachment** score was now moderate (50th percentile), which reflected Jill's increased understanding of Alison's needs. The **reinforces parent** score was now low (1st percentile), demonstrating a significant change in Jill's perceptions about Alison's desire to interact with her.

Positive attachment and reciprocity were observed during the mother-child interaction, where Jill spent 100% of the time interacting and sharing attention with Alison, again despite the fact that Alison did not consistently share attention with Jill.

7.8 Discussion

Figure (7.6) demonstrates the difference between events and states, the process from Jill's initial feelings of lack of competence as a result of not being believed by her husband and other friends and family members, and her perception of the interaction between her daughter and her husband being better than it was with her and her daughter. This resulted in her feeling rejected by her own child and blaming herself for not being able to interact with her daughter. These difficulties and perceptions resulted in Jill feeling angry towards both her husband and her daughter. The anger she felt towards her daughter, the feelings of rejection from her daughter and her uncertainty about whether her daughter loved her resulted in her lacking in confidence and a feeling of not being a competent mother.

There appeared to be a realisation, following the introduction of PECS and the play therapy and with an increase in her understanding of autism along with an awareness of how to get down to her child's level, that she had to change her own behaviour. With that also came the change in her husband's attitude where he began to encourage interaction between Alison and Jill. This change in Jill's behaviour and the change in her husband's behaviour facilitated an improvement in Alison's communication and interaction skills, leading to the breaking down of the barriers that had previously been in the way of Jill and Alison forming an attachment.

Once the assessment commenced and Jill felt that someone else was sharing the burden of the difficulties she had been experiencing, and with the increase in communication and interaction between her and Alison, her confidence as a mother increased, as did her competence. This increase in her competence and

reciprocity between mother and daughter resulted in a strengthening of attachment between the dyad and Jill feeling that she was now a 'proper mother'.

7.9 Refinements to the study

This next section reflects upon the various aspects of the pilot study and gives justification for the refinements made prior to conducting the main study.

7.9.1 Reflections on the interview

The interview yielded some rich data, which was very valuable and gave an excellent insight into the emotions Jill experienced before, during and following assessment and diagnosis of her daughter. These insights would not necessarily have been gained using any other method of data collection, such as a questionnaire alone, as this method made it possible to probe deeper when a question revealed interesting data. It was also possible during the face to face interview to gain insight into Jill's emotions from the non-verbal communications she used throughout. These included crying and laughing which added value to the verbal communication. She was very honest throughout the interview about the negative emotions that she had experienced towards her daughter during this time.

The interview was emotional for Jill but she described the actual process in some ways to be cathartic, which Hutchinson, Wilson & Wilson (1994) describe as one of the benefits experienced by many participants during interviews, as it

provides a sense of relief when the participant is allowed to frankly discuss his/her emotions. Jill felt this sense of relief was due to the fact that she had never had the opportunity to express her own feelings and emotions before, as most of the focus had been on her daughter. The interview process and emotions expressed by Jill were also challenging for myself as, although I have worked for many years with vulnerable parents in a variety of different health settings, I have not experienced such honesty regarding the negative emotions a parent has towards her child. It was possible however to remain professional and offer support in an empathetic way, without being judgemental during the interview. It was possible that the frankness that Jill demonstrated throughout the interview may not necessarily be replicated in future interviews.

7.9.1.1 Potential bias during the interview

As already discussed in the methodology chapter the risk of bias in a study using interview and observational methods can be a real weakness and can pose a threat to the validity of a study. As Guba, Lincoln & Denzin (2008) suggest, bias can be divided into three main categories: reactivity, respondent bias and researcher bias (see chapter 6.8 p. 110). Potential difficulties specific to the pilot interview which may have resulted in bias may have been related to poorly constructed questions, recall bias and social desirability bias. Again, these have already been discussed in depth in chapter 6.8, p. 110. An attempt to minimise the risk of bias during the pilot interview is discussed.

When designing the interview questions an attempt was made to achieve a hierarchy of questions that followed the suggestions made by Kvale &

Brinkmann (2008); however, following the interview it was decided that mothers would be asked to describe their feelings in further depth using adjectives of their choice, which they would be asked to justify using probing techniques such as asking 'why do you think you felt that?'.

The pilot interview was carried out two years and four months after the diagnosis was given, and therefore the potential for recall bias to present a major threat to the credibility of the study using self-report data was very real (Basso, Olsen, Bisanti & Karmaus, 1997). The ability to recall information was discussed in depth with Jill, who explained that given the time since the diagnosis it was now easier for her to reflect upon her emotions. She explained that it would have been very difficult to discuss her emotions in any depth nearer to the time of diagnosis, and she was able to remember clearly what her emotional state was at the time. It is therefore proposed that, despite the potential for recall bias to be a threat, in this case, where emotions were being discussed in depth, the gap between diagnosis and the interview was an advantage and enabled Jill to reflect upon her emotions at the time in a rational way.

7.10 Refinements to the reporting of the data

The pilot study not only allowed for refinements to be made to the data collection, but also for reflections on the data reporting. The collection of the three different types of data would be retained in the main study and each individual type of data would be analysed as per this pilot study; however, the reporting of the data for each case would not entail such in-depth description

within the thesis as this would result in a vast amount of data. Rather, the results of the mother-child interaction and the PSI would be merged with the interview data using the conceptually clustered matrix and the association network, which would be followed by a narrative.

The conceptually clustered matrix included quotes from Jill in addition to the quotes used in the narrative to illustrate points. It was decided that in the main study these quotes would be used in the narrative alone and not in the matrix as it resulted in the matrix being extremely lengthy and difficult to read.

7.11 Refinements to data collection procedures

Certain refinements were made to the data collection procedures which are discussed along with justification for these changes.

7.11.1 The interview

As already mentioned, the interview revealed some rich data and therefore proved very useful as a method of collecting data about such sensitive issues. It is essential however to refine certain aspects of the procedure in addition to the questions asked.

During the interview Jill answered questions that were part of the interview schedule without being asked. This resulted in having to search through the interview schedule in order to ensure that each question had been answered. It

is therefore essential that the researcher is very familiar with all of the questions so as not to have to constantly refer back to the schedule.

The question relating to where the interview should be conducted was discussed with Jill and, despite the fact that the telephone had interrupted the interview twice and her dog became unsettled at one point, she still felt that the home setting was most conducive to feeling relaxed. It was considered that in subsequent interviews it may be possible to ask the participant to minimise these interruptions by putting an answering machine on prior to the interview. However, it was also felt important to acknowledge that the researcher has been invited into the participant's home and should not make too many demands.

7.11.1.1 Reflections on original interview questions

During the interview the original interview schedule was used and every question was addressed. In mixed methods research the research questions are the driving force in the methods used and, as Tashakkori and Teddlie (2006) point out, are vitally important. The reformulation of research questions following data collection, analysis and report writing is thought to be essential (Onwuegbuzie & Leech, 2006).

Therefore, following the iterative process of analysis where the researcher became entrenched in the data, several revisions of the analysis of the interview data were carried out in order that the final modification would ensure the optimum results. The questions were therefore reformulated to reflect this process and to also reflect the process of using a mixed method design. Table

(7.4) shows the revised questions (the original interview questions (table 7.2) can be found in section 7.5.1, p126).

Table (7.4) Revised interview questions

	Revised interview questions
1.	Can you tell me a bit about your child?
2.	Can you tell me when it was that you went through the process of assessment and diagnosis?
3.	Can you explain to me in what way you felt that there was something different about………………. before the assessment? (Additional prompts) Can you explain that further or give me examples?
4.	Can you tell me what it was about………….. that worried you more than anything else before the assessment started? (Additional prompts) How did that make you feel?

5.	How did you feel about interacting with ………….. has it always been easy?
	       i. Has this changed at any point?
	      ii. In what way has it changed?

6.	How did ……….. difficulties with communication make you feel? (Additional prompts) Did you ever feel disappointed?
7.	How did ……….. difficulties with interaction make you feel? (Additional prompts) Did you feel disappointed?
8.	Can you explain to me whether you think that your child's difficulties affected the way you felt about him / her? (Additional prompts) Can you use some words to describe the way you felt?
9.	Did you receive any strategies to help with communication? (Additional prompts) Can you tell me what difference, if any, they made? How did that make you feel?
10.	Did you receive any strategies to help you interact with ………………? (Additional prompts) Can you tell me if they made a difference? How did that make you feel?
11.	Do you think that the difficulties you experienced during the assessment process affected your relationship with your partner?
12.	Can you describe whether you ever had any negative feelings about ……………….? (Additional prompts) Why do you think you had these? Was there anything that helped you overcome these feelings?
13.	Can you explain whether there was anything about the way that the professionals who were involved in the assessment or intervention behaved that made things either easier or more difficult?
14.	Was there anything during the period of assessment that you think helped you to come to terms with the diagnosis better? (Additional prompts) Can you explain why?
15.	Is there anything else you would like to tell me?

There is a hierarchy of questions to be used during an interview, and the language used in the interview must be sensitive and reflect the concepts used by the participants (Kvale & Brinkmann, 2008). They suggest that the initial questions should be open-ended such as 'tell me what it was like before', then moving into the intermediate questions which probe deeper about the concept such as 'how did you feel?', and finally using ending questions such as 'how have your views changed?'. The change in the interview questions have attempted to reflect this hierarchy.

7.11.2 The mother-child interaction observation

During the videoing of the mother-child interaction and the coding of the interaction several issues came to light that would benefit from being refined.

When Jill entered the room in the Child Development Centre she immediately commented on feeling odd playing with her child in a strange place. Following the play session she was questioned about where she would feel more comfortable playing with her child. She suggested that although it may have been more comfortable for her to participate in the observation at home, this would definitely have certain drawbacks such as the child and mother becoming distracted by the telephone, the television, other people in the house and other toys in the room. Therefore, following consideration of the advantages and disadvantages of the different settings, a decision was made to continue to carry out the observation in the CDC.

During the session Jill attempted to engage Alison in play with the various toys which were sited throughout the room and included table top activities. The

focus of the play however became the toys and Jill had to follow Alison around the room in order to maintain the interaction. As a result it was difficult to measure the time spent in joint attention. It was therefore decided that future sessions would involve the toys being sited on a comfortable mat on the floor, which prevented the need to move around the room and therefore the potential for the child to become distracted. The mother was also encouraged to play with her child in any way she preferred and therefore not necessarily with the toys. This is supported by research carried out by Kasari and Sigman (1997), in which they chose to focus the observation on the interaction rather than on a toy.

7.11.3 The Parenting Stress Index

Jill was asked to complete a further PSI based upon her present feelings and emotions ('later emotions') following the interview and video of mother-child interaction. The results from this questionnaire did reflect her present feelings which she had disclosed during the interview. In the main study therefore mothers were asked to complete two PSI questionnaires. The first was based upon their present feelings and emotions (later emotions) prior to the interview, and the second was based upon their emotions and feelings, during the time of assessment and prior to the introduction of therapies (early emotions), following the interview. It was anticipated that by discussing and reflecting upon the earlier emotions during the interview, they would be more able to reflect upon these emotions during that period and complete the questionnaire accordingly.

7.12 Disclosing my personal involvement with autism

Interviews and qualitative research are, by definition, dependent upon the relationship and the interaction that develops between the researcher and the participant (Perry et al., 2004b). These authors suggest that the nature and the quality of the relationship will be developed throughout the interview, and the quality of that relationship may affect the richness of the data being generated. It was anticipated that, given the nature of the emotionally laden questions, developing trust and a rapport with the mother was essential. As already discussed, social desirability phenomena (Barriball & While, 1994) (chapter 6.8.2 p.111) may affect the way in which the participant responds to the researcher, which is dependent upon their perceptions of the researcher. Because of the potential effects of social desirability phenomena, a decision as to whether to disclose to the mother that I was also a parent of a child with autism had to be made. If I did disclose this information to the mothers this may have resulted in an immediate rapport between us as they shared a common lifestyle. The mothers may have assumed that I was empathic and had a true understanding of their situation. On the other hand, as is the nature of autism, all autistic children are very different and the way that each individual mother copes with the stresses of having a child with autism will be very different. The mothers may therefore not have disclosed their true feelings, opinions and beliefs if they felt that I might have dealt with the stress in a different way or may have been judgemental in any way. Therefore in order to assist with this decision I asked Jill, who knew that I had an adult child with autism, whether having this knowledge had made the process easier or more difficult. She was unwavering in her response that it had made her feel far more comfortable, as

she felt we had a shared understanding. A decision was therefore made to disclose this information to all of the mothers.

7.13 Conclusion

The pilot study was carried out in order to refine the procedures for data collection, analysis and reporting of the results. Several modifications were carried out at every stage during this pilot study in order that the procedure for the main study would be seamless. The next step in the research was to recruit mother-child dyads from the diagnostic pathway and carry out further individual case studies based on the modifications of this pilot study.

The next chapter will present the following five individual case studies based on phase one of this study.

CHAPTER EIGHT

RESULTS FROM INDIVIDUAL CASE STUDIES

The previous chapter presented the pilot study which was carried out as a full case study prior to the main study. Justification for amendments to the data collection and analysis were given. This chapter presents the results from the remaining five individual case studies.

8.1 Presentation format for case study data

The results from each individual case study are presented in this chapter and utilise the analysis strategies of phase one of the analysis plan as described in chapter (6.6.1, p.102) Each case study includes:

- Short cameo and demographic information

- Timeline of assessment and diagnosis

- Conceptually clustered matrix

- Association network

- Narrative

All case studies are presented in a similar way; however, the association network from case study five is depicted over two pages as it was too complex to present on one page.

The results from case study one are not presented within this chapter as they have already been presented in chapter seven: The pilot study.

Each conceptually clustered matrix (Miles & Huberman, 1994) includes five different types of cell entries which have been used to present a synthesis of the findings from the different data collection methods, and are presented in table (8.1). In order to easily view the different cell entries a colour coding scheme has been used for the conceptually clustered matrix for case study two as an example.

Table (8.1) Cell entries for conceptually clustered matrix

Themes	Themes that were developed as a result of coding the interview data, the results of mother-child interaction and the PSI.
Child nodes	Hierarchical nodes derived from coding interview data which, along with the results from the other data go towards the development of the themes.
Ratings	These are taken directly from the analysis of the numerical data: • High, moderate, low for the PSI • Very positive, positive, neutral, negative, very negative for the mother-child interaction
Short summary phrases	Used to explain or qualify a rating.
Statements	Observations made by researcher.

All of the children except the unusual case (Gail and Emily) were assessed by a consultant community paediatrician, a specialist speech and language therapist in autism, a specialist educational psychologist in autism and a specialist learning disability nurse. The specific assessments used with each child are described in table (6.1), p.89.

8.2 Case study two (Sally and Duncan)

Sally, aged 36, is separated from the father of her children. Her eldest son, Duncan, has a twin brother, and she also has one younger daughter. Sally does not go out to work but stays at home to look after her three young children. At the time of the assessment and diagnosis Sally did not have any support from her children's father as he was abroad and did not see his children. At the start of the research Sally was living with her new partner and he provided considerable support with her children. Table (8.2) summarises the demographic information for this case study.

Table (8.2) Demographic characteristics of the mother and child: case study two

Demographic characteristics

Age of mother	36
Race	White British
Relationship status during assessment	Single
Other children	Two
Employment	No
Age of child at diagnosis	34 months
Gender of child	Male
Diagnosis	Autism spectrum disorder
Additional diagnosis	Learning disability
Language level at start of assessment	Non-verbal
Length of assessment	20 weeks
Age of child at start of research	64 months

At the age of two years 10 months Duncan was diagnosed with an autism spectrum disorder and an additional learning disability. The assessment lasted 20 weeks, during which time Duncan started attending a specialist day nursery for children with autism and learning difficulties. Duncan has remained in this school placement since his diagnosis. The timing of assessment, interventions and diagnosis can be seen in figure (8.1).

Figure (8.1) Timeline of assessment, diagnosis and interventions: case study two
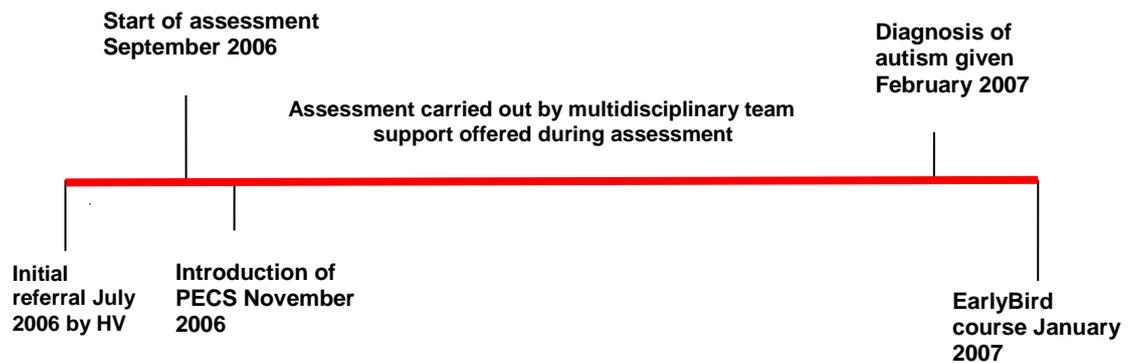
Start of assessment September 2006

Assessment carried out by multidisciplinary team support offered during assessment

Diagnosis of autism given February 2007

Initial referral July 2006 by HV

Introduction of PECS November 2006

EarlyBird course January 2007

PECS - Picture Exchange Communication System (Bondy & Frost, 2001)

EarlyBird (Shields, 2001)

Table (8.3) Conceptually clustered matrix: Themes emerging from interview data, Parenting Stress Index and observation of mother-child interaction: case study two

Qualitative themes	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Attachment	**Mother didn't feel loved** **Mother felt lack of attachment with her child** **Heartbroken because he didn't know or care that she was his mother**	**(Attachment) High (97th percentile)** Mother had difficulties with understanding what her child wanted and did not feel that he knew she was his mother and therefore wanted her more than anyone else.	**A more natural relationship where she is not always trying to teach him things** **He has a better understanding of the world which allows him to have fun**	**(Attachment) Low (25th percentile)** Understanding what he wanted is now only 'somewhat difficult' and she now feels that he knows she is his mother and wants to be with her more than anyone else.	**50% very positive and 50% positive** The mother's affect and time spent in shared attention **(90%)** gave an impression of the mother's positive attachment with her child..
Reciprocity	**He showed no recognition in his eyes**	**(Reinforces parent) High (100th percentile)** Felt that her child did not like her and did not want to be close to her. Felt that her child rarely did things that made her feel good.	**Mother now believes that he loves her because he will look at her and echo that he loves her** **Reciprocal happiness because he is happy when she is happy**	**(Reinforces Parent) High (95th percentile)** This remained high as she still felt that her efforts were not appreciated. She did however now feel that her child liked her and now wanted to be close to her.	**Positive reciprocity** The child's behaviours were **40%** neutral, **40%** positive and **20%** very positive. *There was a true sense of each enjoying the other's company.*
Competence as a mother	**Didn't feel like a proper mother** **Blamed herself for his difficulties**	**(Competence) High (100th percentile)** This mother expressed not feeling successful or good at being a parent and did not enjoy it.	**Started to feel as though she had a sense of purpose**	**(Competence) High (91st percentile)** Although she still did not feel that she was a good parent she now enjoyed being a parent and felt that she was now successful.	*Very confident with interaction and in managing her child.* *Maintained his attention through interactive play.*

Mother's affect	Situation resulted in clinical depression Felt guilty for having negative feelings	(Depression: mother) High (100th percentile) High due to feelings of guilt, sadness and anger related to her child. (Mood: child) High (100th percentile) Described her child as being very moody, easily upset and always being in a bad mood.	Extreme happiness when he asked for something for the first time	(Depression: mother) High (91st percentile) Although this remained high she no longer felt responsible for her child's behaviours (Mood: child) High (90th percentile) Although she felt that her child still cried and fussed more than most other children she no longer felt that he was constantly in a bad mood.	Very positive (50%) Positive (50%) *Mother's mood was extremely warm and enthusiastic during the interaction. She appeared to enjoy the interaction with her son.*
Relationship with others	Felt resentment of friends and family's lives She felt that the relationship with her other children suffered because they always had to take a back seat Family and friends didn't understand				
Diagnostic process			Goals and honesty eased the pain Supportive experience		
Effects of interventions			EarlyBird promoted acceptance of the diagnosis due to better understanding PECS helped her become a mum Was able to see him for what he was and not just an autistic child Felt more able to understand the autism Felt able to think about the future		

Figure (8.2) Association network for case study two

Negative   Mother's affect   **Positive**

1. Lack of interaction

6. Mother didn't feel loved

10. Meeting other parents gave her hope

15. Child better understands the world

2. No recognition she was his mother

7. Lack of attachment from mother

18. Saw him for who he was and not just the autistic child

11. Understanding the autism

19. A more natural relationship

3. Family & friend's lack of understanding

8. Not a proper mother

16. Ability to think about the future

17. Realisation that he could communicate

9. Depression

4. Resented the fact her life was ruined

12. Learning how to help him communicate

20. Reciprocal happiness

19. Believing he now loves her

13. Developed a sense of purpose

5. No emotional attachment from child

14. Professional support, time and goals helped with acceptance of diagnosis

Legend on page 141

Time
Antecedent variables   **Mediating variables**   **Outcome variables**

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8.2.1 Narrative for association network: case study two

It is possible that Duncan's lack of interaction, ability to signal recognition for his mother and lack of emotional attachment (1,2 & 5) resulted in Sally feeling as though Duncan did not love her (6) and almost as if it was a conscious decision on his part not to interact or engage with her:

> *'He would look at me and be with me out of necessity, but there wasn't really any love in his eyes'* (NVivo line number 352)

This insecurity about whether she was loved, and the fact that Duncan did not demonstrate any emotional attachment, appears to have resulted in a lack of attachment (5) from Sally's point of view (7):

> *'I don't think I had much emotional attachment at first because I wanted him to progress, but for me it was more about just making life a bit better'* (NVivo line number 429)

This lack of what she described as 'emotional attachment' or being loved appears to have caused Sally great distress. This lack of attachment (7) and her perception of how a mother should feel towards her child, based on her experience with her other children, resulted in her feeling that she was not a 'proper mother' (8):

> *'A mum just has this innate ability to comfort her child and the child, regardless of whether they know it or not, will be comforted by the mum. I just thought me being a mum for him was pretty pointless, because I couldn't comfort him I didn't know what he wanted and I didn't make him feel better. So what was my point'* (NVivo line number 516)

Sally's perception of not being loved by Duncan resulted in her 'feeling resentment' at having a child with a disability and that her 'own life was ruined' (4):

> *'I couldn't do a thing. So it would get on my nerves, and I would feel very sorry for myself but this was the rest of my life, and when he is*

> *30 am I still going to be chained to him in the house and I would feel very sorry for myself that my life was now over. Then, ever so guilty because that's how I felt, because it wasn't his fault'* (NVivo line number 366)

Although Sally was not explicit in describing the effects of her family's lack of understanding and her resentment towards her friends who had children without any difficulties, it appears that these issues may have further reinforced her feelings of not being a 'proper mother' (8):

> *'Not a clue how hard it was as they knew I had a child with difficulties, but they weren't understanding with the ins and outs. The silly things that make this day so difficult so yes one or two very supportive, but they didn't really understand. And some who just didn't grasp that at all'* (NVivo line number 629)

> *'they had no idea how hard it was. And I kind of resented them. My friends with other children'* (NVivo line number 615)

Sally's perception that her life was ruined and that Duncan did not love her, together with the lack of understanding from her family and friends, resulted in Sally developing clinical depression (9):

> *'Lots of antidepressants for three years that's the only thing that got me through the day for years and I tried stopping taking them and then the desperate sadness and gravity of stuff I had to do to just to make it through the day was too much just too much'* (NVivo line number 653)

Meeting other parents during the EarlyBird course (10) and beginning to understand how autism had affected Duncan (11) appears to have enabled her to start to think positively about the future which she had previously been unable to do.

> *'Acceptance only came at EarlyBird'* (NVivo line number 729)

> *'About four weeks ago I mentioned something about his future and he said that's the first time that I have ever heard you talk about his future'* (NVivo line number 72)

Understanding the autism (11) and learning to help him communicate through the use of PECS and strategies learnt on the EarlyBird (12) brought about a

realisation that Duncan was able to communicate (17) which she had previously been unaware of:

> *'That was the start, and understanding the triad of impairments and just figuring out a little bit of how his brain was wired. That was…I just wish everyone could have just had that hour of just understanding how the brain might function, as it makes a world of difference'* (NVivo line number 550)

Duncan being able to communicate and share attention with her appears to have resulted in her now believing that he did love her (20):

> *'I know he loves me'* (NVivo line number 385)

Sally had previously felt redundant as a mother (8). However, learning how to communicate with Duncan provided her with a sense of 'purpose' (13):

> *'I started to have a bit of purpose, as his mum. Again, that was probably my wanting it to be me. Had he learned PECS with somebody else he would have gone and asked them. But I was the person that was doing it and I hope that at that point then he had some trust in it'* (NVivo line number 563)

 An overarching phenomenon, which was experienced during the assessment, was the support that she felt she was given by the professionals, and having time to discuss her fears and anxieties as well as the setting of goals all helped her to accept the diagnosis (14):

> *'I was actually dealt with really really well. I was always told when I saw someone that you will see us again at this time, or you will have an outcome by then and I will tell you the date. I was always kept informed of what was happening and where we were going. So I felt the process that I went through was as nice as it could have been. Nice is the wrong word, but it was handled in the best way I thought it could possibly have been'* (NVivo line number 702)

> *'I was very lucky that I had a very supportive experience of the diagnostic process'* (NVivo line number 699)

Sally's ability to think about the future (16) and her feeling that she now had a 'purpose' in Duncan's life meant that for the first time she was able to see him

for who he was and not just as a child with autism and significant difficulties (18):

> *'I see him now without wanting to change him'* (NVivo line number 53)

These factors, as well as her understanding that he could communicate, appear to have resulted in her experiencing what she described as 'a more natural relationship' with him (19):

> *'we've got that kind of relationship now, whereas before it was all I'm trying to teach him to do this and trying to, it was always trying to draw him out and trying to desensitise him trying to overcome this and to overcome that and now to just.....we just have a silly time'* (NVivo line number 90)

Finally, her belief that he now loved her (20), the more natural relationship they had (19), and Duncan's better understanding of the world (15) resulted in both Sally and Duncan taking pleasure in, and finding joy in, each other's happiness (21):

> *'his understanding of life now is so different. He wants to have fun. He wants to share fun and I can actually now see and foresee where we might actually be happy. Which there was none of that back then it was all just hard work'* (NVivo line number 665)

Sally described feeling a lack of attachment initially and this is reflected in her early PSI **attachment** scores (97th percentile) which later changed to the 25th percentile. This later score was also reflected in the scores from the mother-child interaction (50% very positive and 50% positive), and the observation that both appeared to enjoy each other's company. Interestingly, however, the **reinforces parent** scores did not change considerably (100th percentile to the 95th percentile), indicating possibly that she still did not feel that her child was a source of positive reinforcement.

Sally described the transition from feeling as though she was not a 'proper mother' and feeling redundant to eventually having a sense of purpose and feeling positive about her ability as a mother. This was observed during the mother-child observation where Sally appeared extremely confident throughout the interaction and was able to maintain Duncan's attention despite the fact that his behaviours were 40% neutral. This observed behaviour was not reflected however in her PSI **competence** scores which were initially at the 100th percentile and remained high at the 91st percentile. It is possible that these scores were a reflection of her perceptions of her own ability and were affected by her **depression** (100th percentile and 91st percentile on the PSI).

8.3 Case study 3 (Delia and Jake)

Delia, who is aged 30, lives with her long-term partner who is the father of both of her children. Her youngest son Jake was diagnosed at the age of three years with an autism spectrum disorder. She has an older son of ten years who has a diagnosis of Asperger's syndrome. Delia works part-time at the weekends when her partner cares for the children. Table (8.4) summarises the demographic information for this case study.

Table (8.4) Demographic characteristics of the mother and child case study three

Demographic characteristics

Age of mother	30
Race	White British
Relationship status during assessment	With long-term partner
Other children	One
Employment	Part-time
Age of child at diagnosis	36 months
Gender of child	Male
Diagnosis	Autism spectrum disorder
Additional diagnosis	Learning disability
Language level at start of assessment	Non-verbal
Length of assessment	12 weeks
Age of child at start of research	39 months

At the age of 36 months Jake was diagnosed with an autism spectrum disorder and an additional learning disability. Following the diagnosis Jake started at a specialist nursery for children with autism and learning difficulties. Jake has remained in this school placement since his diagnosis. The timing of assessment, interventions and diagnosis can be seen in figure (8.3).

Figure (8.3) Timeline of assessment, diagnosis and interventions; case study three
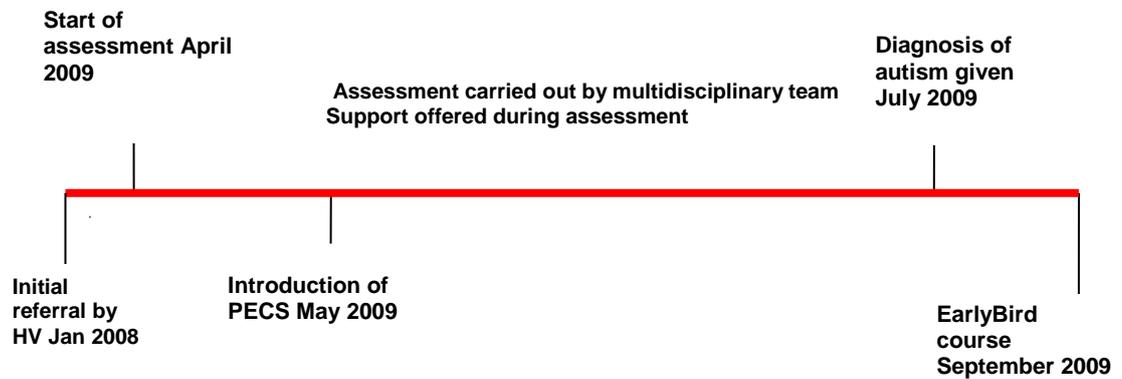
Table (8.5) Conceptually clustered matrix: Themes emerging from interview data, Parenting Stress Index and observation of mother-child interaction: case study three

Qualitative themes	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Attachment	**Unsure of his love** Memo coding: because he could not communicate his feelings this mother didn't know whether he loved her **Difficulty making a connection**	(Attachment) Low (25th percentile) This score was low; she was negative only about how easy it was to understand what her child wanted, otherwise she would have scored 0%. (# See comments in Later emotions PSI)	**Improvement in mood due to easier interaction** **Felt needed**	(Attachment) Low (1st percentile) When scoring this time she felt that it was now very easy to understand her child. Therefore there was a considerable improvement in her attachment score. # During the interview and during the observation of the mother-child interaction Delia became slightly defensive when questioned about her relationship with Jake.	Neutral 66% of this mother's interactions were neutral with only 33% being positive. (Child's behaviours were 60% negative, 20% neutral and 20% positive). *Delia used appropriate visual strategies and was down at her child's level trying to maintain joint attention throughout. However her affect and physical contact were lacking in quality and her language was not always appropriate for her child's level of communication development.*
Reciprocity	**Difficulty understanding his feelings for her**	(Reinforces parent) High (97th percentile) Expressed feelings of not being appreciated and her child not doing things to make her feel good. However she did feel that her child liked her.	**His achievements affect her mood and it was improved with his increased and improved interaction** **Change in mother's behaviour had positive effect on child**	(Reinforces parent) Moderate (85th percentile) Following interventions she felt that her child now does things to make her feel good.	Shared attention (90%) Despite the mother's difficulties in trying to engage her child she nevertheless maintained joint attention for 90% of the session.
Competence as a mother		(Competence) Moderate (45th percentile) Before interventions she described having had more problems bringing up her child than she had expected.	**Didn't need interaction to feel like a better mother** Memo coding: this mother was very anxious to appear competent. When asked about her interaction	(Competence) Moderate (25th percentile) Following interventions she experienced bringing up her child being easier than she had previously.	Neutral and positive Despite her child's behaviour scores being 60% negative, 20% neutral and only 20% positive she nevertheless was able to engage him in shared attention for 90% of the time. It may have been however that his negative behaviours had an effect on her behaviour.

			with Jake her voice became much louder in response, almost as if she was being slightly defensive.		
Diagnostic process	**Worried he would not get a diagnosis**		**Relieved by diagnosis**		
Effects of interventions	**Support made relationship easier**	(Depression) Moderate (82nd percentile) Mother described feeling guilty when she got angry with her child. She felt that most of his behaviours were her fault.	**Understanding the autism** **The effects of support** **Length of assessment facilitated support** **Increase in interactions** **Changing her own behaviour**	(Depression) Low (35th percentile) Mother now felt stronger and no longer felt that his behaviours were her fault.	
Needing to be normal			**Wanted him to be like other children**		
Relationship with partner	**Partner not involved with problems** **Didn't share anxieties with partner** **Relied on support from own mum**	**Before interview** (Spouse) High (85th percentile) Mother reported that since having her child they did not spend as much time together as she had expected.	**Mum used information gained from EarlyBird to inform partner**	(Spouse) Moderate (70th percentile) She now felt that they were able to make time for each other.	

Figure (8.4) Association network for case study three

Negative — Mother's affect — Positive

9. Didn't share anxieties with partner

10. Relied on support from others rather than partner

11. Mother now confident to talk to partner about autism

2. Difficulty understanding his feelings for her

1. Lack of communication and interaction

5. Unsure of his love

16. Understood the autism

3. Difficulty making a connection with her child

12. Professional support

17. Felt needed

20. Improvement in mother's affect

4. Mother felt used as a tool

13. Interventions

6. His achievements affected her mood

15. Improved interaction

18. Relieved by diagnosis

14. Length of assessment facilitated supportive environment

7. Anxious to appear competent

8. Needed him to be like other children

19. Change in mother's behaviour had a positive effect on child

Legend on page 141

Time
Antecedent variables — Mediating variables — Outcome variables

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8.3.1 Narrative for association network: case study three

The antecedent variable (1) of Jake's lack of communication and interaction resulted in Delia having difficulty in understanding Jake's feelings for her (2):

> *'when he was younger I didn't know how he was and how he was feeling because he couldn't tell me. Sometimes, you did, just think as I said that you could have been anybody as long as that person got him the things he wanted'* (NVivo line number 404)

This resulted in her struggling to make a connection with Jake (3) and her feelings of being 'used as a tool' (4), which in turn further exacerbated her difficulty with the connection. Ultimately this culminated in her being unsure of his love for her (5):

> *'Sometimes you feel you're just someone there who, you know to fetch things, give him things'* (NVivo line number 393)

Delia had felt very anxious that a diagnosis of autism would not be given because this would have left her in a great deal of doubt about why Jake was different (18):

> *'If they hadn't diagnosed autism it would be like well, what's wrong with him and then we would have to go through more you know, like not tests but assessments and stuff like that'* (NVivo line number 691)

Delia descried how his 'achievements' in interaction and communication affected her mood (6) and she described being very anxious to appear competent as a mother (7). His difficulties or successes in his achievements with communication and interaction affected her mood dramatically.

> *'I think it just made me feel good because he felt that he could come to me and he knows that he felt safe with me and stuff like that'* (NVivo line number 423)

> *'I didn't get depressed or anything by it. But like I said, because I know he's making progress and every time he does something, an achievement making progress etc it makes me feel better. I know*

he's coming on and that makes me feel a lot better' (NVivo line number 356)

She talked extensively about her needing him to be like other children and wanting him to be normal (8). Her desire for him to be 'normal' or like other children also affected her mood:

> *'Oh it was great, it was brilliant. You know it was really good. You just felt so proud, and as I said it's like Jake is doing things what children do every day and it's probably nothing to them, but it's you know, when he does an achievement like that. You know it makes me really really happy'* (NVivo line number 382)

Delia had great difficulty in sharing her anxieties about Jake with her partner (9) and relied heavily upon support from friends and family rather than from him (10):

> *'My partner is not really the one who likes to get involved with things because he's quite a laid-back person. He is just quite happy for me to do the parenting role'* (NVivo line number 552)

> *'I have had a lot of support from my mum, I've had a lot of support from my mum. I basically relied on her'* (NVivo line number 554)

Once Delia began to understand how the autism affected Jake (16), as a result of the professional support that she was offered (12) and the interventions (13) received, she developed confidence to discuss her anxieties and the concept of autism with her partner (11), leading to improved relations:

> *'I think our relationship is a lot better because I think I understand him more now and I know why, I know if he is naughty and stuff like that. I know it's not because he is being naughty it's because of the way he is. I was never angry but probably before he got diagnosed I was probably more stressed and I had a lot more anxiety. But as I said once he got his diagnosis I was a lot happier. But I think it really is because I understand him more. I mean it is nice to have a normal relationship with your son. So basically just that I am a lot happier'* (NVivo line number 708)

The professional support and interventions (12, 13), along with a change in Delia's behaviour (19), resulted in an improvement in Jake's interaction and communication. This resulted in Delia feeling needed as a mother (17):

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'Well, it's just a lot easier and I mean he just interacts with me now. I don't have to keep asking him you know Jake look or listen or, you know his eye, his focus on me now is, he looks at me when he talks to me now. I mean, sometimes he does get a bit distracted but it's nothing major, now but we can like have a proper game and he interacts with me if we are reading a book he will look at me and he will you know tell me what's going on in the book. And yes, but you know it is so much better now' (NVivo line number 273)

Delia felt that the time the assessment had taken facilitated her acceptance of the diagnosis because this resulted in her receiving support for a longer period of time (14):

'Actually, I think I preferred it to be over a period of time because it also gave me, knowing that I had the support for longer, and as you said, I got to know everyone better' (NVivo line number 645)

Delia realised that if she changed her own behaviour this resulted in a change in her child's behaviour (19).

'Because like with the EarlyBird course and all the information that I have been given about autism. It's given me the knowledge, so I know exactly how to interact with him and to get through to him' (NVivo line number 300)

Ultimately, feeling needed along with being relieved by the diagnosis of an autism spectrum disorder (18) resulted in an improvement in Delia's affect (20):

'I was glad that he did get the diagnosis of autism, because at least then I knew why. Because even before he got the diagnosis I had the feeling that you know that he is going to turn out to have autism. But I was more relieved because then I knew that was definitely the reason why he was the way he was' (NVivo line number 687)

'But now I know myself that he wants me for me. Ehm because he's always wanting to, you know….. He always wants to hug me and be with me and stuff like that and it's just something I know myself. I know he wants me for me now' (NVivo line number 397)

Unlike the other mothers from this study, at no point during the interview did Delia discuss feeling as though she was not a good mother nor did she ever blame herself for Jake's difficulties. This was reflected in her **competence** scores on the PSI (45th percentile and 25th percentile). Interestingly, however,

on the early emotions **depression** score on the PSI she did state that she felt that most of his behaviours were her fault (85th percentile), whereas the later emotions score reflected that she no longer felt they were her fault (35th percentile). Delia was anxious for Jake to be like other children and was very eager to appear as a competent mother. During the observation of the interaction, although she did use a variety of visual strategies to gain and maintain Jake's attention, her affect and physical contact were extremely limited as was the quality of her language appropriate to Jake's ability, despite gaining information about these strategies during the PECS and EarlyBird training. Her scores during the interaction reflected this observation (33% positive and 66% neutral).

During the interview Delia did discuss being uncertain about Jake's love for her and, despite her **attachment** scores being low on both occasions on the PSI (25th and 1st percentiles), her **reinforces parent** scores were high and at the extreme end of moderate (97th and 85th percentile). This was also seen in Jake's scores during the interaction (20% positive, 20% neutral and 60% negative).

It appears therefore that there is a conflict between the reporting during the PSI and the observations made during the interaction and the results from the interview, and it is possible that with Delia an element of respondent bias came into play.

8.4 Case study four (Sheila and Jack)

Sheila is aged 38, and is married with one other child who is younger than Jack. Sheila was a staff nurse but had to give up work to care for Jack because she found it difficult to find childcare for him. She now stays at home to look after her children. Table (8.6) summarises the demographic information for this case study.

Table (8.6) Demographic characteristics of the mother and child: case study four

Demographic characteristics

Age of mother	38
Race	White British
Relationship status during assessment	Married
Other children	One
Employment	No
Age of child at diagnosis	56 months
Gender of child	Male
Diagnosis	Autism spectrum disorder
Additional diagnosis	Learning disability
Language level at start of assessment	Non-verbal
Length of assessment	17 weeks
Age of child at start of research	65 months

At the age of 56 months Jack was diagnosed by the multidisciplinary team. Prior to the diagnosis Jack had started at a specialist nursery for children with autism and learning difficulties. Jack has remained in this school placement since his

diagnosis. The timing of assessment, interventions and diagnosis can be seen in figure (8.5).

Figure (8.5) Timeline of assessment, diagnosis and intervention; case study four
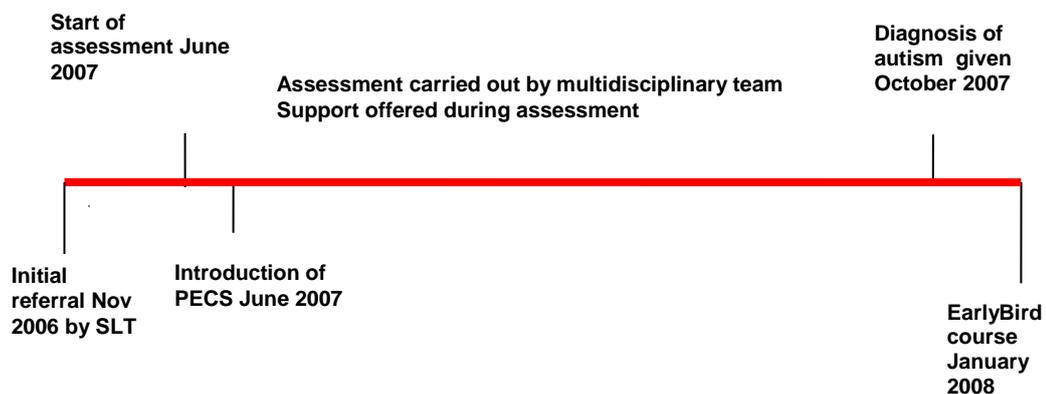
PECS = Picture Exchange Communication System (Bondy & Frost, 2001)

EarlyBird (Shields, 2001)

Table (8.7) Conceptually clustered matrix: Themes emerging from interview data, Parenting Stress Index and observation of mother-child interaction: case study four

Qualitative themes	Interview	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Attachment	**Disappointment and anger** **Interaction was one-sided** **Failed as a mother** **Didn't feel she loved him**	Before interview (Attachment) High (95th percentile) Mother described finding it very hard to understand what her child wanted and expected to feel closer to her child than she did. (Reinforces parent) High (100th percentile) She did not feel her child did things to make her feel good. She was not sure if her child liked her or wanted to be close to her. She also stated that her child did not like to play with her.	**Increased interaction resulted in increased love**	(Attachment) Low (35th percentile) She now felt that it is easy to understand what her child wants and has close feelings for her son. (Reinforces parent) Moderate (80th percentile) She now felt that her child did do things to make her feel good; however, she still felt that her child did not like to play with her.	Neutral 66% of this mother's interactions were neutral and only 16% were positive and 16% were negative. (Child's behaviours were 20% positive and 80% negative.) *Very little reciprocity. Mainly one-sided from the mother. There were a couple of occasions when he did engage with her by looking at her and she immediately smiled back. She led most of the interactions.* *Shared attention (60.5% of time) was quite difficult as the child was quite passive and did not initiate any activity during the session. He was obviously happy and relaxed in her company.*
Competence as a mother	**Lack of confidence** **Wasn't a good mum because he didn't communicate**	(Competence) High (96th percentile) She described having more problems raising her child than she had expected, she did not feel successful when trying to get her child to do something or handle things, and she felt that she was a person who has some trouble being a parent.	**Became a better mother**	(Competence) Low (35th percentile) She now described herself as not having any problems raising her child and feels successful in what she does most of the time. She also now described herself as a better than average parent.	*Mum did try to engage him but she did not use many supportive strategies such as giving choices, being face to face, being down at his level, playing a game that would engage him, pausing, or following his lead.*
Diagnostic process			**Relieved by diagnosis**		

			Assessment process was helpful **Professionals took the burden** **Time frame was beneficial**		
Effects of interventions			**Understanding the autism** **Getting down to his level** **Interventions gave hope** **Effects of increased interactions** **Saw him for the first time**		
Needing to be normal	**Communication essential to have a place in society** **Trying to make him normal**		**Accepting him for who he is**		
Relationship with partner	**Difficulty communicating fears with partner**	(Spouse) Moderate (50th percentile) She described her child having caused problems in her relationship.	**Help with our communication with each other**	(Spouse) Low (35th percentile) She still felt that her child caused more problems in her relationship with her partner than she had expected; however, she now strongly disagreed that her child caused problems with other relatives.	

| Mother's affect | **Guilt**

Self-blame | Depression High (97th percentile)
She described considerable feelings of guilt, unhappiness, sadness and anger.
Child mood High (96th percentile)
Mother described her child as being difficult and moody. | **Relief**

Happiness | Depression Moderate (75th percentile)
She no longer experienced feelings of guilt, anger or sadness although she did still feel responsible when her child misbehaves.
Child mood Medium (50th percentile)
She still felt that her child was difficult at times. | |

Figure (8.6) Association network for case study four

Negative — Mother's affect — **Positive**

1. Disappointment with and anger about child
8. Unable to discuss fears with partner
10. Gradual acceptance of the diagnosis
13. Burden of guilt lifted
14. Increased understanding of autism
12. Diagnosis helped her understand it was not her fault
6. Tried to make him normal
22. Accepting him for who he is
9. Process of assessment
4. Didn't feel love for child
19. Mother able to talk to professionals about emotions
20. Hope
23. Increased feelings of love
24. Became a better mother
5. Felt a failure as a mother
18. Increased communication & interaction
2. Resented having to make all the effort to interact
21. Saw him for the first time
7. Lack of confidence and competence
17. Mother and partner able to communicate
16. EarlyBird
3. Mother blamed herself for his lack of communication and interaction
15. PECS enabled appropriate interactions

Legend on page 141

Time
Antecedent variables — Mediating variables — Outcome variables

8.4.1 Narrative for association network: case study four

Sheila described feeling disappointment and anger about having a child with difficulties with communication and interaction (1), and resented the fact that she had to make all of the effort to interact and communicate with him (2). This was reflected in her attachment score on the PSI which was at the 96th percentile.

> *'I think at the time, I just felt really, I just felt disappointed, it was my fault, I just felt very disappointed and very angry. I think that was the biggest thing just felt disappointed because he wasn't the same as other kids. Why me'* (NVivo line number 516)

> *'so I was making all the effort'* (200)

She felt unable however to discuss her disappointment and fears with her partner (8):

> *'But in our relationship it was just a little bit, we didn't speak, we talked about it but it was like okay it was happening and there is not much we can do. Besides that there was just the non-speaking side of things like 'are you all right'. It was just that lack of communication between the two of us'* (NVivo line number 489)

She talked about trying to make Jack normal like other children (6), and felt that in order to have a place in society one had to be able to communicate like 'others'. However, she felt that she had failed to achieve this:

> *'I was trying to do too many things, trying to get in, I don't know I was just hoping that just suddenly he would pick it all up, and then he would be fine. I think I tried too hard too much for him so maybe I should have just took a step back and just looked at the bigger situation. Whereas I didn't want to. I think I was very much tunnel vision with it and I was focusing on getting him speaking and talking and everything in any way. So anything he did or said or made a sound I thought that's brilliant'* (NVivo line number 307)

> *'I think it was just the fact that I think if you got communication with anybody in any way you can get through life. Whereas if you can't communicate then you can't………… you're never going to be able to stand up in society. You know you're not able to and that's what I…….. that's what it was for me I just needed him to and wanted him to be able to talk to me'* (NVivo line number 325)

She expressed resentment at having to make all the effort to interact. This resentment in addition to variables (1, 6 & 8) resulted in her not feeling love for her child (4).

'At the time I didn't feel as much love as I do now' (NVivo line number 661)

Sheila blamed herself for Jack's lack of communication and interaction (3). This self-blame and her lack of feelings of love for Jack (4) resulted in her feeling a failure as a mother (5):

'A failure' (NVivo line number 260)

'Because I thought it was my fault I thought I was doing something wrong. That's what I thought' (NVivo line number 358)

This caused her to experience a lack of confidence and competence (7) reinforcing her sense of inadequacy as a parent, reflected in her competence score which was on the 95th percentile:

'Probably very strained really, very tentative with him, I was a little afraid. I didn't know how to handle him or whether I was doing things right, if it was me was it my fault' (NVivo line number 659)

The process of assessment (9) enabled Sheila to gradually accept that Jack had an autism spectrum disorder (10):

'No it wasn't a shock at all because of the nature of the way the assessment had been carried out and the amount of time it took, and the things that the professionals were saying that Jack was doing, that we realised yes hang on a minute he does do that. It made us realise that this is definitely a diagnosis of autism. So no it was not a shock at all at the end of the 16 weeks when we got that diagnosis I think we were expecting it' (NVivo line number 627)

Sheila was relieved by the diagnosis as it helped her to understand that his difficulties were not her fault (12), and the burden of guilt diminished (13):

'so when we got the diagnosis it was kind of, like it was almost like a relief' (NVivo line number 145)

Furthermore, the assignment of a diagnosis meant that she was able to hand over some of the burden to the professionals:

> *'It was literally when we met the professionals, the things they were saying like that Jack was not doing at the time, you know the typical behaviour like lying on the carpet, the things he was doing they just made it sound like well we were not the only……. that was more helpful than anything, it was like, honestly it was just like a big release it was really at the time, I never thought, it was like a big weight had been lifted off my shoulders'* (NVivo line number 367)

Sheila's increased understanding of autism and how to communicate at Jack's level of ability (14) increased her understanding of her son:

> *'I think it's just been a learning process for all of us, I mean for all of us. In know how to interact with him and understanding what his difficulties are'* (NVivo line number 227)

The interventions and the tasks she was given initially to work on with Jack gave her hope that he was going to make some progress. However, it also gave her unrealistic expectations that he may eventually be 'alright':

> *'When we got the speech and language therapy in. I mean they were giving us things to do with Jack and he was making a little bit of progress. It's just that it made me feel well you know we are going to get somewhere or he will be alright'* (NVivo line number 377)

Because she now appreciated that there was a reason for his behaviours she felt able to accept him for who he was (22) and this gave her hope for the future (20). Through this recognition, Sheila described 'seeing' Jack for the first time (21) which resulted in an increase in her feelings of love for Jack (23) and she described becoming a better mother (24):

> *'Yes over time, again the autism course the EarlyBird course, that was like an eye-opener, and it wasn't me it wasn't me. That's what it felt like that's what it was like. That's what I needed. The worry was sort of taken away from me'* (NVivo line number 271)

> *'I think it was the fact that we saw Jack for the first time, for the first time, it sounds terrible doesn't it. We saw Jack for the first time'* (NVivo line number 242)

The introduction of PECS enabled Jack to use what Sheila perceived to be appropriate interactions. This, along with EarlyBird, resulted in increased communication and interactions (18), providing Sheila with hope:

> *But it was when he actually began to start to use it and make sentences with it and I thought hang on a minute this is fantastic because he was actually speaking some words in an appropriate manner and I remember thinking it was fantastic, absolutely fantastic'* (NVivo line number 403)

She expressed delight in how Jack wanted to interact with her and she did not have to initiate or make all of the effort:

> *'Happy, I'm happy that he is like that, that he is wanting to interact with me and to play, wanting me to do things with him. I'm absolutely thrilled and made up that he is like that'* (NVivo line number 213)

Furthermore this increased interaction enhanced her confidence and abilities to discuss her fears and anxieties with her partner (17):

> *'We were able to say to each other 'why he is behaving in that way' and it's only then that one of us will go, come on, hang on a minute it might not be that, let's see what it is'* (NVivo line number 503)

Despite Sheila reporting that her interactions with Jack were much easier after developing strategies on the parent training course and following the implementation of PECS, this was not observed during the mother-child interaction (16% positive, 66% neutral and 16% negative). Sheila did try to engage Jack but she did not use any of the strategies she reported having learnt. This perception was also reflected in her **competence** scores on the PSI which changed from the 96th percentile to the 35th percentile, indicating that she felt she was a competent parent. The interaction observed was very one-sided as it was mainly Sheila that initiated an interaction or a communication with Jack who was extremely passive (20% positive, 80% negative).

As described in the interview, Sheila felt that the difficulties with the interaction being one-sided resulted in her not feeling as though she loved Jack, which is reflected in the **attachment** score on the PSI (95th percentile), whereas once she gained confidence in her own ability her attachment to Jack improved (35th percentile).

8.5 Case study five (Jane and Tom)

Jane, who is aged 40, is a mother of five children. Her two youngest sons aged 12 years and four years eight months both live with her and her long-term partner. Her youngest son Tom has a diagnosis of an autism spectrum disorder. Jane's partner is the father of Tom. Jane does not go out to work but stays at home to look after her two sons. Jane's partner is unemployed and is also at home full-time. He has therefore been able to offer Jane support with caring for the children. Table (8.8) summarises the demographic information for this case study.

Table (8.8) Demographic characteristics of the mother and child: case study five

Demographic characteristics

Age of mother	40
Race	White British
Relationship status during assessment	Lives with long-term partner
Other children	Four
Employment	No
Age of child at diagnosis	43 months
Gender of child	Male
Diagnosis	Autism spectrum disorder
Additional diagnosis	Learning disability
Language level at start of assessment	Non-verbal
Length of assessment	Five weeks
Age of child at start of research	56 months

At the age of three years seven months Tom was diagnosed with an autism spectrum disorder. The assessment lasted five weeks, during which time Tom attended a local mainstream nursery. Tom has remained in this school placement since his diagnosis. The timing of assessment, interventions and diagnosis can be seen in figure (8.7).

Figure (8.7) Timeline of assessment, diagnosis and interventions for case study five
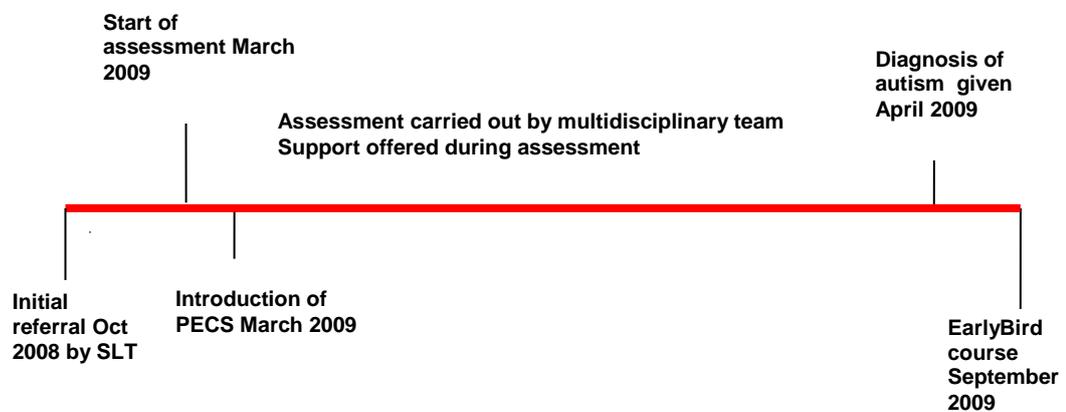
PECS = Picture Exchange Communication System (Bondy & Frost 2001)

EarlyBird (Shields, 2001)

Table (8.9) Conceptually clustered matrix: Themes emerging from interview data, Parenting Stress Index and observation of mother-child interaction: case study five

Qualitative themes	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Attachment	**Blaming child for not making the effort to interact** **Wanting to be loved** **Parents should naturally be able to communicate**	(Attachment) High (80th percentile) This mother felt that her child did not know who she was and did not want her more than any other person. (Reinforces parent) High (99th percentile) This mother was unsure whether her child liked her and wanted to be close to her. She was also unsure as to whether her child disliked her. She felt that her child smiled at her much less than she expected and that her child did not appreciate any effort that she made to do things for him.	**Improved communication** **Believing he now loves her**	(Attachment) Low (35th percentile) Following the interview this mother felt that her child did know who she was but remained unsure of whether he wanted her more than any other person. (Reinforces parent) High (86th percentile) Following interventions she felt more sure that her child liked her and wanted to be close to her. She was still uncertain about whether her child appreciated her efforts.	**Mother** Positive 33% Neutral 66% **Child** Positive 20% Neutral 20% Negative 60% ***Comments on quality of attachment*** *Mother only became animated when her child initiated an interaction by looking at her.* *Mother did not appear very animated and only appeared to enjoy the interaction when he sat upon her knee (said in the interview that she felt loved when he was physically close to her).*
Competence as a mother	**Ashamed she wasn't able to parent properly** **Self-blame** **Felt she was being judged** **Felt she was a bad mother**	(Competence) Medium (40th percentile) This mother did not feel that she was successful in trying to get her child to do something and described herself as an average parent.		(Competence) Medium (60th percentile) Following interventions she no longer described herself as being able to handle things.	***Comments on competence and confidence*** *Initially the child had his back to the mother which she did not try to rectify. Face to face was only regained when child moved himself.* *Quite a lot of directing him rather than following his lead.* *Mother did use quite a lot of gestures to*

					support her communication e.g. pointing, patting knees, hand over hand, shaking head. *Very little commenting. Mainly questions or directions.* *She used some long phrases e.g. 'I think the baby's waking up now and the baby wants some dinner'. Other phrases were one word phrases.* *Not always following child's lead.* *Using language rather than physical prompt to get his attention e.g. 'come back'.*
Diagnostic process			**Goals and information** **Support** **Process** **Time** **Relationship with professionals**		
Effects of interventions			**Getting down to his level** **Insisting on joint attention** **Improved interaction** **Understanding the autism** **PECS helped her to understand him** **PECS brought them closer**		

Mother's affect	**Denial** **Depression** **Disappointment** **Sadness** **Embarrassment** **Self-hate**	(<u>Depression: mother</u>) High (100th percentile) Before interventions this mother felt guilty, angry and sad about her ability to bring up her child and her feelings towards her child. (<u>Mood: child</u>) Medium (60th percentile) Despite this mother's feelings of guilt and sadness she did not describe her child's mood as being difficult.			(<u>Depression: mother</u>) High (96th percentile) Following the interview, although her depression score was lower than previously, she still described having feelings of guilt, sadness and anger. (<u>Mood: child</u>) High (85th percentile) Following intervention she felt that her child appeared to cry more often than other children.	
Needing to be normal	**Wanted him to be normal**					
Relationship with others	**Difficulty facing other parents**		**Difficulties brought her and her partner closer together**			

Figure (8.8) Association network for case study five

Mother's affect

12. Meeting other parents helped her to feel she was not alone

18. Better relationship with partner due to shared understanding

16. PECS

21. Closer relationship

13. Getting down to his level

→ Continued

15. Understanding the autism

20. Improved communication and interaction

14. Insisting on joint attention

17. Understood him as a person

22. Now believes he loves her

19. Professional support, time and goals helped with acceptance of diagnosis

Mediating variables

Outcome variables

8.5.1 Narrative for association network: case study five

Jane's ultimate desire was for Tom to demonstrate in some way that he loved her (11):

> *'I would desperately love for him to turn round and say mummy I love you'* (NVivo line number 206)

Initially Jane denied that there was a problem, not only to others but also to herself:

> *'I think you're kind of in denial, you're hoping that when you go through the diagnosis and you come out the other end that everything is going to be fine'* (NVivo line number 67)

Because of his difficulties in verbal and non-verbal communication (1) and her inability to understand his difficulties, this resulted in her feeling that he was in some way choosing not to communicate with her. Jane therefore blamed Tom for not making any effort (2):

> *'He was like six or seven months old but then it just stopped and he wasn't bothered, he just wasn't trying to interact with us or trying to get our attention or trying to ask for anything. He was just a little loner and wanted to do his own little thing'* (NVivo line number 105)

Jane felt that mothers should instinctively understand their children (3) even if they are not able to communicate. She expressed feeling desperately disappointed and embarrassed about her child's lack of communication skills, which lead to her developing depression (8):

> *'well I did try to think I'm not disappointed about my little boy but I was disappointed'* (NVivo line number 222)

She felt ashamed in front of other parents about having a child that did not communicate and she blamed herself for this (6, 7). Jane disclosed how she 'hated' herself for having such feelings:

> *'It's quite sad really when you feel you should be able to communicate with your child even without speech. You know you should be able to pick up on what they are trying to tell you without communicating verbally but he just doesn't show any of that'* (NVivo line number 152)

> *'you think you feel disappointed in your child because they have got these disabilities and then you hate yourself for thinking that'* (NVivo line number 219)

She also had a strong desire for him to be normal (4):

> *'All I want is for him to be normal or able, whatever the word is'* (NVivo line number 233)

These antecedent variables (1, 2, 3, 6 and 7) resulted in her feeling unsure of Tom's love for her (5) and therefore she described herself as being a 'bad parent' (9):

> *'His difficulties with communication make you feel a lot of ways they make you feel like you are a bad parent'* (NVivo line number 200)

Jane also perceived that she was being judged by other people regarding her abilities as a mother (9). This led her to avoid social situations and reinforced her sense of maternal inadequacy (10):

> *'Do they just think I am a bad parent for letting him do this. Because it is quite hard isn't it to face people'* (NVivo line number 80)

During the EarlyBird Jane was able to meet other parents who were in the same situation which enabled her to feel that she was not alone in her situation (12):

> *'God EarlyBird was really good because it taught you a lot of things that you wouldn't think about. It taught you how to get through to your child and how to do certain things with your child. Especially taught me how to understand him which I think was the main thing'* (NVivo line number 508)

This also helped her to understand her son's autism (15), and how to get down to his level of communication (13):

> *'you do have to get down on their level to be able to express yourself, because if you don't they just get frustrated and angry and*

> *you just get frustrated and angry. So basically I've learned how to cope with him and I've learnt how to communicate as best I can and the most important thing is that I can understand him now, I can understand nearly everything'* (NVivo line number 551)

Jane felt that the PECS played a role in bringing them closer together (16):

> *'I would say the communication with the PECS, you know the symbols. Because once he sort of got that and figured that out he would just give us the card and we would know what he wanted then and I think that gave him that little bit of confidence to get involved with another person. So it brought us that little bit closer'* (NVivo line number 173)

This understanding of how to communicate with Tom gave her the confidence to insist on her child sharing attention with her (14). These changes in Jane's understanding and the changes in her own behaviour resulted in an improvement in Tom's communication and interaction (20):

> *'He will get involved now, if he wants you to play he will give you some toys, if he is struggling with something he will say mummy help or daddy help so you know that he wants you to help him'* (NVivo line number 160)

As similarly expressed by Sheila, with the introduction of PECS and this increase in her understanding of her child, she was able to see her son for the first time as a person in his own right (17):

> *'He knows now he's just got to show us the picture put on the strip and we will understand him as a person'* (NVivo line number 342)

Jane also felt that other factors, such as the support and the relationship she developed with the professionals, had aided in her coming to terms with her son's difficulties (19):

> *'I just think that when he was diagnosed when we all sat round the table and they said we've come to the conclusion that he is autistic I just sank but then I looked up and they were offering me enormous support so I think that was very helpful because I realised all I needed to do was ask and everyone that I had met over the diagnosis time would be there to help'* (NVivo line number 528)

> *'It did seem quite long and lengthy but good reason and I think that was helpful cos I developed a relationship with everyone you know over that time'* (NVivo line number 442)

Not only was there an improvement in the quality of her relationship with her child, but there was also an improvement in the quality of her relationship with her partner as she felt that they now had a shared understanding:

> *'I think maybe it's brought us that little bit more together hasn't it because we've got that little bit of understanding you know because he belongs to us because our little boy has brought us that little bit closer to each other'* (NVivo line number 386)

This improvement in Tom's communication and interaction resulted in Jane perceiving that she and Tom had a closer relationship, and therefore she now believed that her son loves her (22):

> *'He does now sit on my knee and put his arms around me and I suppose that is his way of saying he loves me'* (NVivo line number 212)

Despite Tom having considerable difficulties with interaction and communication which were observed during the interaction (20% positive, 20% neutral and 60% negative), Jane attempted to engage him using a variety of strategies although she did not appear very animated in her interactions (positive 33%, neutral 66%). Jane described having learnt several strategies during the PECS and EarlyBird training; however, interestingly her **competence** scores on the PSI increased from the 40th percentile to the 60th percentile. This is possibly because she was now more aware of her difficulties with interaction and an increased awareness in her **child's mood** (60th percentile to the 85th percentile). Her **attachment** scores however suggested that there was an improvement in her sense of emotional closeness to Tom (80th percentile to the 35th percentile). This is despite the **reinforces parent** score remaining high (99th percentile to the 86th percentile).

Although Jane discussed during the interview her perception that her child now loved her, she nevertheless still had an extremely high **depression** score (100th percentile to the 96th percentile).

8.6 Case study six (Gail and Emily) (unusual case)

Gail, who is 38 years old, has two children. She has a son of 22 months and a daughter, Emily, who at the age of seven years was diagnosed with Asperger's syndrome. Gail is a single parent and is divorced from the father of her two children. Gail is a qualified teacher but does not go out to work as she cares for her two young children. Table (8.10) summarises the demographic information for this case study.

Table (8.10) Demographic characteristics of the mother and child: case study six

_____

Demographic characteristics

Age of mother	38
Race	White British
Relationship status during assessment	Single parent
Other children	One
Employment	No
Age of child at diagnosis	Seven years
Gender of child	Female
Diagnosis	Asperger's syndrome
Language level at start of assessment	Verbal
Length of assessment	Eight weeks
Age of child at start of research	Seven years four months

At the age of seven years Emily was diagnosed by a paediatric psychiatrist and a specialist nurse with Asperger's syndrome. Assessments included:

- Autism Diagnostic Observation Schedule (Lord et al., 2000)

- Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002)

Emily attends a mainstream school and was referred for assessment by the local consultant community paediatrician. The assessment lasted 8 weeks; Gail was seen once for the DISCO and the mother-child dyad was seen once for the ADOS following which the diagnosis was given. The timing of assessment, interventions and diagnosis can be seen in figure (8.9).

Figure (8.9) Timeline of assessment, diagnosis and interventions case study six

Unlike the other mother-child dyads, where a PSI was carried out both prior to and post interview and reflected emotions during assessment and diagnosis and current emotions, the PSI in this case was only carried out once because the time between assessment, diagnosis and this study was only four months.

Table (8.11) Conceptually clustered matrix: themes emerging from interview data, Parenting Stress Index and observation of mother-child interaction: case study six

Qualitative themes	Interview (Negative emotions)	PSI	Interview (Positive emotions)	Mother-child interaction
Attachment		(Attachment) Low (25th percentile) Felt that it was easy to understand what her child wanted and felt that her child wanted her more than other people. (Reinforces parent) High (99th percentile) Felt that her daughter rarely did things to make her feel good and wasn't sure whether her child wanted to be close to her. She also felt that when she did things for her child her efforts were not appreciated.	**Strong bond** **Knew her daughter loved her** **Felt needed**	**Mother** Positive 50% Neutral 50% **Child** Very positive 40% Positive 60% ***Comments on quality of attachment*** *This child in comparison to the other children had very good communication and interaction skills which made it easier for the mother to engage with her.*
Diagnostic process	**Disappointed diagnosis took so long** **No time for questions**		**Empowered by the diagnosis** **Let herself off the hook**	
Competence		(Competence) Medium (45th percentile) This mother expressed having had more problems raising her child than she had expected and did not feel that she was always successful. She did state however that she felt that she was a better than average parent.	**Understands that she needs to help her daughter** **Able to accept her daughter for who she was**	***Comments on competence and confidence*** *This mother appeared to be very confident when interacting with her daughter. She commented after the session that that was the first time she had ever played that type of game with her daughter. She allowed her daughter to lead the game but did take control back again when her daughter appeared to be trying to take control.*
Mother's affect	**Initially blamed herself for her daughter's difficulty** **Questioned her skills as a mother** **Frustrated by her daughter being hard work** **Resented some behaviours**	(Depression: mother) Medium (30th percentile) This mother did not express any feelings of guilt, sadness or anger. (Mood: child) High (99th percentile) She did however score her child as being very moody and easily upset and felt that she cried more often than most children.		

Figure (8.10) Association network for case study six
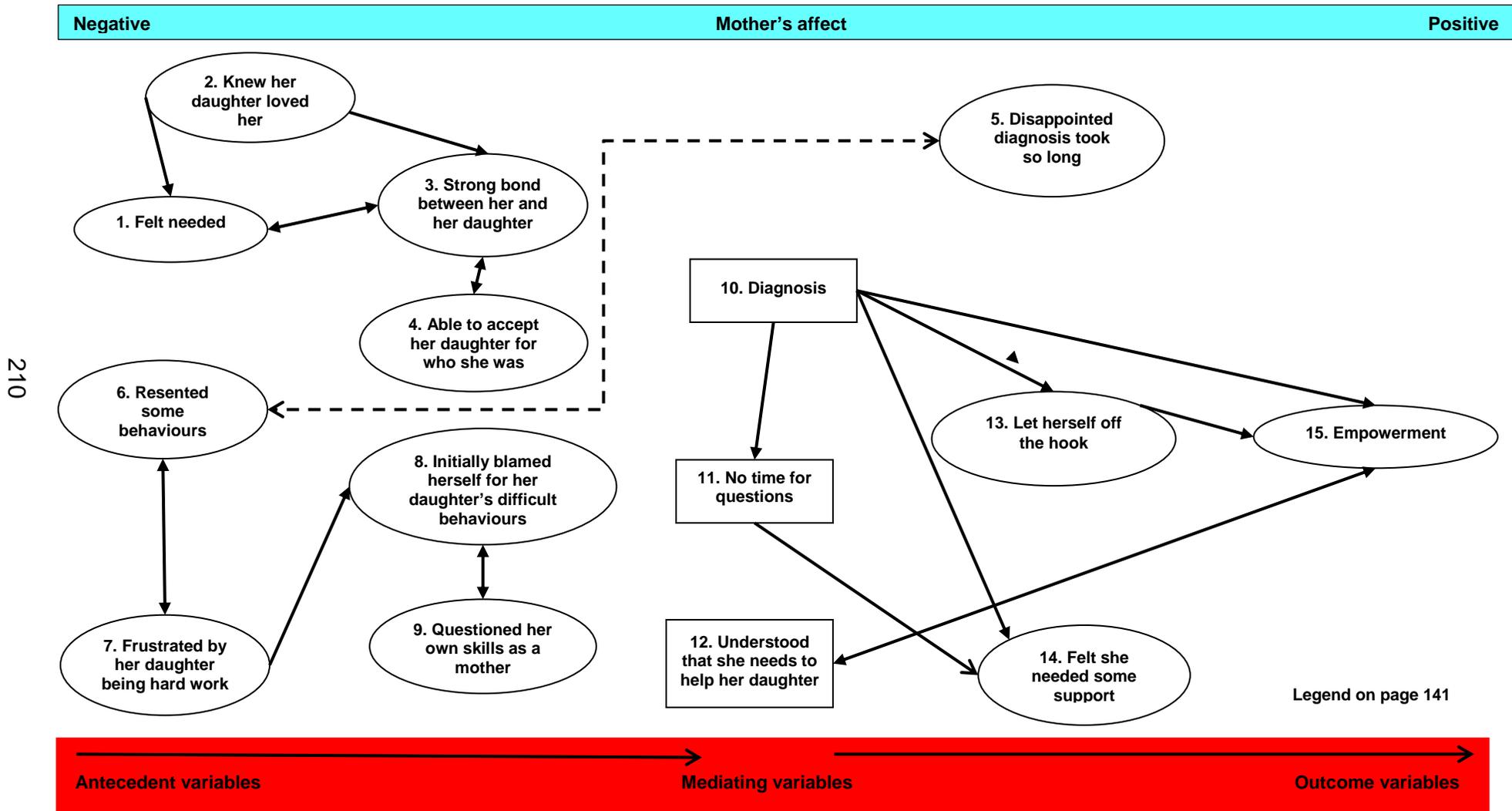
8.6.1 Narrative for association network: case study six

Gail felt needed by her daughter (1). She knew by her daughter's behaviour that she was loved by her (2) which resulted in a strong bond or attachment between them (3):

> *'I can see that she needs me, and I can see that I am fighting the fight for her, and I can see that I am the one to help her with the Asperger's and to deal with life. It is my responsibility to make sure that she is equipped to deal with life. So I can see how much she appreciates all that'* (NVivo line number 436)

Because of this bond she felt able to accept her daughter for who she was (4) and did not initially see the difficulties Emily was experiencing with inflexibility or empathy. She did however resent some of her behaviours (6) and found herself frustrated by the fact that she found Emily 'hard work' (7):

> *'I slept with her every night and I never had a night off and I resented that'* (NVivo line number 315)

> *'I remember feeling frustrated and I put the blame on myself I thought perhaps I was doing things wrong'* (NVivo line number 212)

It took ten months before this mother-child dyad was seen for assessment, which appeared to reinforce Gail's resentment of the behaviours and also compounded her self-blame for Emily's behaviours (5):

> *'when I first got the diagnosis I did, I felt disappointed that I had been through all of that. I had been through all of that, for myself I felt kind of like I had been through a marathon and finally I felt really sad for what she had been through, all of those years of people not understanding why she was different'* (NVIVO line number 545)

Because her daughter presented with difficult behaviours and because she blamed herself for the inability to control these behaviours, this resulted in her questioning her own skills as a mother (9):

> *'Well the problem with me is that I probably put that on myself. I certainly did with Emily I took the blame for that I took the blame for her not doing what she should do'* (NVivo line number 286)

Once she was given the diagnosis (10) she felt that she was able to let herself 'off the hook' (13) for her inability to manage her daughter's behaviours:

> *'Well I just thought I can let myself off the hook a bit with Emily because I thought yes Emily was different, she was harder and I did the best that I could with her and people were telling me you should do this with her and you should do that with her and she should behave'* (NVivo line number 295)

She did state however that she was not given any time at the diagnostic meeting to ask any questions (11):

> *'I didn't really know what to expect I thought I was going to be able to ask questions and I wasn't what I was told that I would have a follow-up appointment and I am still waiting for that and I just thought it was such big news and I kind of felt I was just in and out and that was it'* (NVivo line number 747)

The lack of opportunities for discussion meant that Gail was left wanting support for her daughter's diagnosis and instruction in how to manage her behaviours (14). The diagnosis, however, seemed to give this mother a sense of empowerment (15), as she realised that she was not responsible for her daughter's behaviours and that she was able to help her manage her behaviours and the effects of the Asperger's (12):

> *'I am wondering whether I am feeling empowered actually'* (NVivo line number 450)

> *'there is more of an understanding there and it is much more a case of how am I going to help with this rather than why the hell is she not listening to me'* (NVivo line number 539)

Despite Gail stating how close she was to her daughter, and how she knew that she was loved by her daughter, she had a very high score for the **reinforces parent** domain (99th percentile) on the PSI, in which she reported that she did not know whether her daughter wanted to be close to her. Her **attachment** score was at the 35th percentile indicating that she felt a sense of emotional closeness to Emily. Interestingly, Emily's scores on the interaction observation

were 40% very positive and 60% positive which appears to have resulted in her mother finding it easy for her to interact and communicate with her.

8.7 Conclusion of findings from individual case studies

The results from these individual case studies are interesting and informative in their own right, and raised some salient issues with respect to understanding how each mother conceptualised her relationship with her child and the factors which influenced the relationship. However, to further understand the dynamics of the mother-child relationship it is essential to explore the themes that have emerged by carrying out cross-case analysis.

The following chapter introduces phase two of the analysis plan and discusses the conceptual framework and explains how and why this was developed. Other strategies used to carry out the cross-case analysis are also introduced.

CHAPTER NINE

PHASE TWO THE CONCEPTUAL FRAMEWORK AND CROSS-CASE ANALYSIS

The previous chapter presented the analysis of the various sources of data for the single case studies which raised some salient issues and aided in the understanding of the mother-child relationship. In order to understand in greater depth the dynamics of this relationship, further exploration was carried out using a conceptual framework to direct the cross-case analysis (phase two). The development of this conceptual framework is discussed in this chapter.

9.1 Introduction

The single case analysis resulted in nine themes being identified as being significant in the mother-child relationship. These themes were developed following in-depth analysis of all the cases using the tactics of noting patterns and themes, making contrasts and comparisons and noting relations between variables (a full description of each tactic provided in chapter 9.4.3, p.220).

This chapter will discuss phase two of the analysis plan (see figure 9.1), which commences with the justification for using a conceptual framework and its development, followed by a description of the cross-case analysis.

Figure (9.1) Phase two of the analysis
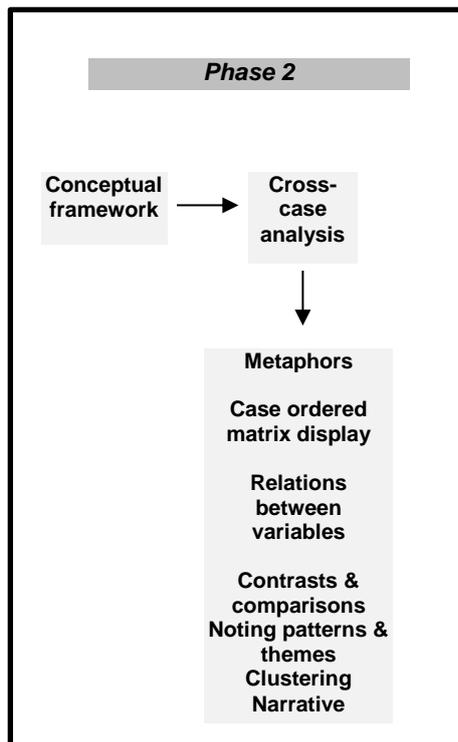
9.2 The need for a framework

After having completed the within-case analysis it became evident that in order for the analysis to move from the descriptive into a deeper level which enabled the connection of existing knowledge, a conceptual framework needed to be developed which would present a lens through which to interpret the relationship. It was considered that the use of a conceptual framework would allow for the critical evaluation and interpretation of the theoretical assumptions developed from the within-case analysis and move to a richer cross-case interpretation (Miles & Huberman, 1994). Therefore a theoretical framework which focused specifically on the development and maintenance of interpersonal relationships was explored, which could be used to develop the conceptual framework specifically for this study.

The previously considered literature offered several different theoretical frameworks which have been used to analyse and understand relationships (see chapter 4, p.31 for a full review). It therefore seemed appropriate to consider the applicability of one of these theoretical frameworks to develop a conceptual framework for this study.

9.3 Developing the framework

In order to understand and describe the highly complex process of the dyadic relationship between mothers and their autistic children, the conceptual framework developed for this study was based upon Hinde's (1979; Hinde, 1995) theory of interpersonal relationships (see chapter 4.4, p.37 for an in-depth discussion of Hinde's relationship theory).

Hinde (1995) proposed using categories to explore dimensions of the relationship which include: *The content of the interactions, the diversity of the types of interactions, the qualities of the interactions, the relative frequency and patterns of interactions, the reciprocity or complementarity of the interactions, intimacy* and *satisfaction.* Although this conceptual framework was not developed until after the analysis of the mother-child interaction observation, the categories described by Hinde (1995) were consistent with those of Doussard-Roosevelt et al. (2003), Watson (1998), Horowitz et al. (2005) and Lemanek et al. (1993) which were used in the development of the observation instrument (see chapter 6.4.2, p. 93).

In addition to suggesting categories in which the relationship can be observed, Hinde (1995) also proposes dimensions or relationship components which can

facilitate the analysis and exploration of the relationship. He argues that appropriate external and internal dimensions are essential to establish the basis from which to view and understand these phenomena (see figure 9.2). These dimensions include: an 'operative system' which has a specific goal such as nurturance, play etc.; 'function of the parent' within the behavioural system such as the mother's affect; 'interpersonal qualities' such as responsiveness; 'facilitators and barriers' which may affect the relationship, such as the nature of the disability and level of support provided to the family; and 'outcomes'.

Following the analysis and integration of the individual sources of data eight major themes were developed. When exploring these themes it was possible to integrate each theme into one of Hinde's dimensions which enabled the focusing and interpretation of these findings between cases rather than just at an individual level. These dimensions were re-named as: *dynamic interactions*, *function of mother within the dynamic interactions*, *personal qualities, facilitators and barriers* and *outcomes.* An integration of the eight themes into this framework is depicted in table (9.1)

Table (9.1) Dimensions from which to view the relationship

Dimension	Themes involved
Dynamic interactions	• Attachment
Function of mother within the dynamic interactions	• Mother's affect • Needing to be normal
Personal qualities	• Mother's competence
Facilitators and barriers	• Relationship with partner • Relationship with others • Diagnostic process • Interventions
Outcomes	**The outcome of each dimension is included in the discussion at the end of each chapter**.

The visualisation of the conceptual framework as a model is often beneficial to the understanding of a phenomena and figure (9.2) depicts a visual representation of the conceptual framework for this study.

Figure (9.2) Conceptual framework illustrating the dimensions used to carry out the cross-case analysis
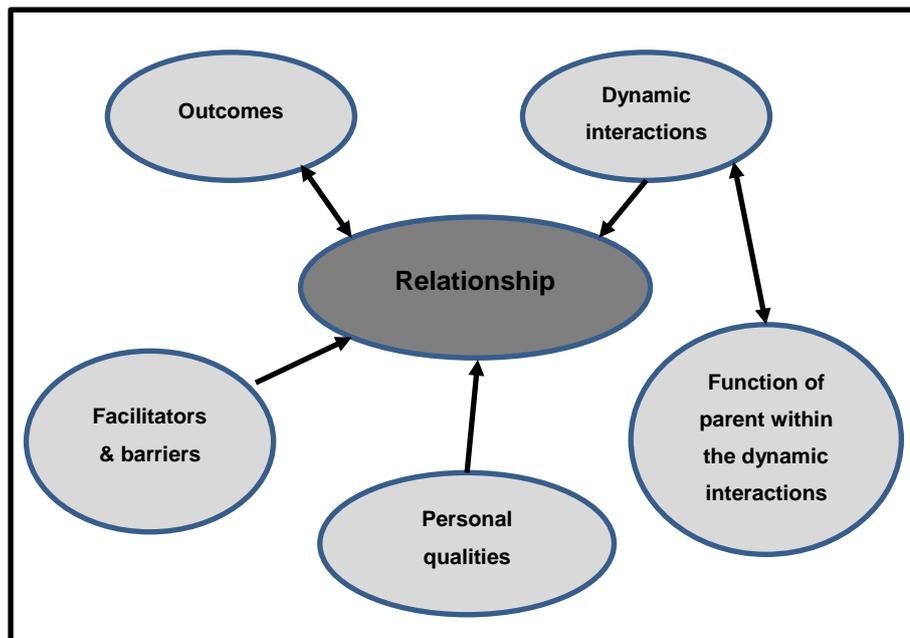
9.4 Cross-case analysis

Phase two of the analysis began with the development of this conceptual framework; however, other strategies as proposed by Miles & Huberman (1994) were utilised in order to carry out cross-case analysis. The process of cross-case analysis, like single case analysis, encompassed several different stages and generated a considerable amount of data. Therefore in order to condense the information, matrices were used which allow for the easy visualisation of the results. The stages of phase two were as follows:

9.4.1 Making metaphors

Metaphors enable examination of what exactly is going on and allow the researcher to not just describe or denote a phenomenon, but to progress to a more inferential and analytical level. Metaphors or analogies are ways of connecting findings to theory (Miles & Huberman, 1994). The use of metaphors enabled the researcher to step back from the data and ask what is happening and develop a concept that was rich and complex and which encompassed the whole story.

Each theme, which was derived from the analysis of the individual case studies, was subject to further analysis and analytical metaphors were developed. See table (9.2) for a list of metaphors. For example, the analytical metaphor 'The reciprocal bond' not only encompasses the mother's attachment/relationship with her child, but also the way in which the child has an effect upon the relationship, and therefore includes several sub-themes (see figure 10.1 for an example). **These analytical metaphors became the new themes and included sub-themes.**

Table (9.2) New themes (Analytical metaphors)

Original theme	New theme (Analytical metaphor)
Attachment	The reciprocal bond
Competence	Being up to the job
Mother's affect	Contradiction of emotions
The diagnostic process	A journey well-travelled
Interventions	A state of transformation
Relationships with others	The challenge of others
Relationship with partner	A precarious alliance
Needing to be normal	Craving normality

9.4.2 Cross-case matrix

This involved developing a cross-case analysis matrix in which data from all cases are ordered according to the theme being explored. A case analysis matrix was developed for each theme and each case was displayed within that matrix. This allowed for the easy visualisation of similarities and differences across cases. This was developed using the same stages as the conceptually clustered matrix for the single case analysis (see chapter 6.6.2, p.104 for a detailed description).

9.4.3 The narrative

This involved the development of a narrative describing the complexity and meaning of the theme. In order to generate meaning from the data the following tactics were used and were based on analysis strategies proposed by Miles & Huberman (1994): noting relations between variables, making contrasts and comparisons, noting patterns and themes, and clustering. These are described in more depth below.

9.4.3.1 Noting relations between variables

This is the process of observing relationships between the metaphors and making theoretical statements about the relationship between concepts rather than descriptive comments about the people.

9.4.3.2 Making contrasts and comparisons

The process of making comparisons and exploring contrasts between people, roles, activities and cases is what Miles & Huberman (1994) describe as a time-honoured way to test conclusions. When analysing the data each case was compared to every other case in order to explore how it differed.

9.4.3.3 Noting patterns and themes

For a general description of noting patterns and themes refer to chapter (6.6.1.1, p.103) 'Coding the interview data' section.

9.4.3.4 Clustering

Clustering is a general name given to the process of inductively forming categories and the iterative sorting of things, events, actors, processes,

settings, and sites into these categories (described within 'Coding the interview data' in chapter 6.6.1.1, p. 103).

9.4.4 Numerical data

The observation of the mother-child interaction and the PSI both provided an additional source of data to validate the themes that emerged from the interview and observational narrative data. The domains from the PSI are represented in bold type. The purpose of using these additional sources of information was to enhance the exploration and description of the individual responses and behaviours of the mothers using simple descriptive statistics. The total scores and scores from the individual domains from the PSI are provided in appendix 13, p.370.

Each chapter will begin with a description of the dimension and the themes encompassed within the dimension, followed by the observation scores and PSI domains included.

9.5 Conclusion

Phase two of this study involved the development of a conceptual framework which was based upon a theoretical framework proposed by Hinde (1995), which was used to view the relationship and interpret it at a deeper level. Each dimension within the conceptual framework is represented by:

- **A cross-case analysis matrix**

- **A results narrative**

Each theme is illustrated by direct quotes from the mothers taken from the interview transcriptions and these are in italics. Both confirmatory and dis-confirmatory quotes are used in the exploration and description of the themes.

The following four chapters provide a detailed presentation of the dimensions and analysis of the themes derived from the integration of the data gained from the interview, the mother-child interaction and the PSI. Each dimension is constructed from themes and sub-themes which are each discussed separately.

CHAPTER TEN

DYNAMIC INTERACTIONS

The previous chapter gave a detailed overview of phase two of the analysis which included the development of a conceptual framework used to frame the cross-case analysis, as well as an in-depth discussion of how the cross-case analysis was carried out. The following four chapters discuss the analysis of the four dimensions.

This chapter comprises the dimension the *dynamic interaction* and encompasses the theme of the **reciprocal bond**. This theme describes the attachment that the mothers had with their children and the reciprocal nature of the joint and shared attention and interaction within the relationship. This theme consists of six sub-themes, represented in figure (10.1) and the cross-case analysis matrix is represented in table (10.1).

These interpretations also include:

Observation: Mother and child behaviours, time spent in shared attention and the qualitative description of the relationship.

PSI: The **attachment** and **reinforces parent** scores

Figure (10.1) Dynamic interactions

Dimension

Dynamic interaction

Theme

The reciprocal bond

Sub-themes

Detachment | Rejection & failure | Unsure of love | Breaking down barriers | Believing that she is loved | Becoming a proper mum
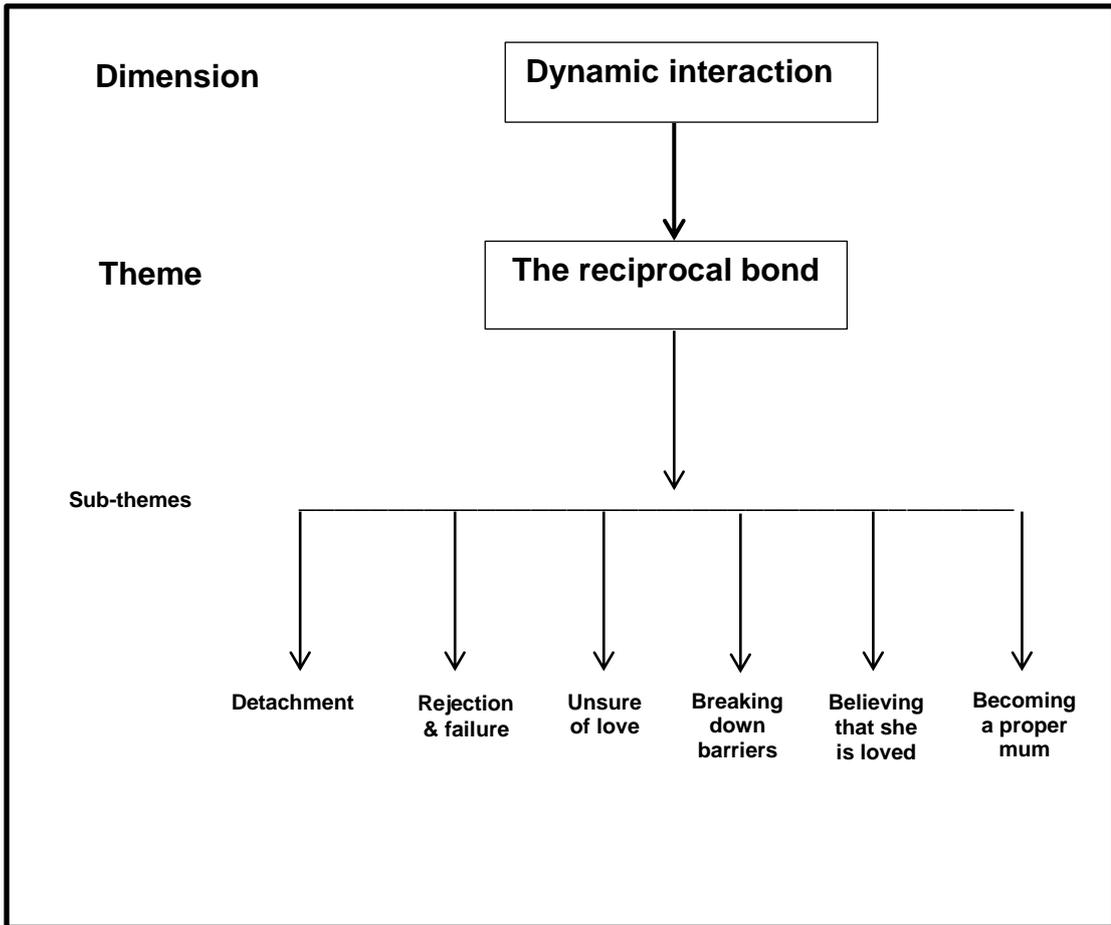
Table (10.1) Cross-case analysis matrix for the reciprocal bond

Cases	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Jill & Alison (1)	**Detachment:** unsure of daughter's and own feelings. Detachment between mother and daughter which resulted in the mother not feeling like a proper mum. **Rejection and failure:** rejection reinforced mother's feelings of failure: no eye contact meant rejection. **Unsure of love:** didn't know if her daughter loved her because she didn't communicate or interact.	Attachment **75th** percentile Reinforces parent **99th** percentile	**Breaking down of barriers:** PECS promoted communication and interaction with the mother. **Becoming a proper mum:** needed the communication and interaction in order to feel like a proper mum.	Attachment **50th** percentile Reinforces parent **1st** percentile	**Mother scores** **Child scores** **75%** positive **14%** positive **25%** neutral **71%** neutral **14%** negative **90% time spent in shared attention** **Quality of relationship** Quality of relationship good. They obviously enjoyed interacting with each other but occasionally mum appeared to be insecure and sought reinforcement from daughter. **Reciprocity between mother and child** Interaction slightly one-sided with mum trying to engage daughter using different strategies.
Sally & Duncan (2)	**Detachment:** no emotional attachment from mother initially. **Rejection and failure:** the effects of her child ignoring her and not interacting with her. **Unsure of love:** mother didn't feel loved as there was no love in his eyes. There was no recognition in his eyes that her child understood that she was his mother.	Attachment **97th** percentile Reinforces parent **100th** percentile	**Breaking down the barriers**: now has a natural relationship: no longer trying to teach him tasks but enjoying him for who he is. **Believing she is loved:** she knows he now loves her because he will look at her and tell her he loves her. His better understanding of the world now allows him to share fun with mum. There is reciprocal happiness where he will take joy in the fact that she is happy.	Attachment **25th** percentile Reinforces parent **95th** percentile	**Mother scores** **Child scores** **50%** very positive **20%** very positive **50%** positive **40%** positive **40%** neutral **90% time spent in shared attention** **Quality of relationship** The quality of their relationship was excellent, her son obviously is very attached to his mum and he enjoyed interacting with her. **Reciprocity between mother and child** Mum used several strategies which she had learnt during the EarlyBird course in order to maintain this reciprocity.

Delia & Jake (3)	**Detachment:** she found it difficult to make any connection between her and her son. **Rejection and failure:** it could have been anyone: mother felt that her son would have been as happy with a stranger as he was with her which she found distressing. **Unsure of his love:** didn't know if she was wanted for her or just to get things.	Attachment 25th percentile Reinforces parent 97th percentile	**Breaking down the barriers**: mother realised that her behaviours affected his behaviours and she was therefore more able to get through to him. **Believing she is loved:** felt that she was wanted and needed for being her not just to get things. **Becoming a proper mother:** his progress made her feel better as a mother; however she didn't need this to feel like a proper mother.	Attachment 1st percentile Reinforces parent 95th percentile	**Mother scores** **Child scores** **33%** positive **20%** positive **66%** neutral **20%** neutral **60%** negative **90% time spent in shared attention** **Quality of relationship** Mother's interaction was slightly strained.
Sheila & Jack (4)	**Rejection and failure:** felt a failure because he could not communicate with her. Interaction was one-sided; she felt that she had to make all the effort to interact with her child. **Unsure of love:** she did not feel that she loved him as much as she does now.	Attachment 95th percentile Reinforces parent 100th percentile	**Breaking down the barriers:** Increased interaction resulted in increased love, and since he started to interact and communicate with her she now feels able to love him.	Attachment 35th percentile Reinforces parent 80th percentile	**Mother scores** **Child scores** **16.5%** positive **20%** neutral **66.5%** neutral **80%** negative **16.5%** negative **65% time spent in shared attention** **Quality of relationship** Shared attention was quite difficult as her child was very passive and did not initiate any activity during the session. **Reciprocity between mother and child** Very little reciprocity, mainly one-sided from the mother.
Jane & Tom (5)	**Detachment:** she felt unable to communicate naturally and blamed herself for not instinctively knowing what it was that he wanted, which resulted in her detaching herself from him. **Rejection and failure:** this mother felt that her child was purposely choosing not to make an effort to communicate or interact with her which resulted in her	Attachment 80th percentile Reinforces parent 99th percentile	**Breaking down the barriers:** with improved communication she now believes that he understands that she can help him and therefore he wants to interact with her. **Believing she is loved:** because he will sit on her knee and hug her she believes that this is his way of saying that he loves her.	Attachment 35th percentile Reinforces parent 86th percentile	**Mother scores** **Child scores** **33%** positive **20%** positive **66%** neutral **20%** neutral **60%** negative **51% time spent in shared attention**

	feeling like a failure. **Unsure of love:** desperately wanted her child to tell her that he loved her.				**Quality of relationship** Mother did not appear very animated and only appeared to enjoy the interaction when he sat upon her knee (said in the interview that she felt loved when he was physically close to her). **Reciprocity between mother and child** Looked at each other whilst sharing a book, which was initiated by child. Mother then reciprocated by smiling back.
Gail & Emily (6)		Attachment **75**th percentile Reinforces parent **100**th percentile	**Believing she is loved:** mother felt that she always had a strong bond which was reciprocal with her daughter. She knew her daughter loved her and felt her daughter appreciated her helping her. She just knew her daughter needed her.	Attachment **25**th percentile Reinforces parent **99**th percentile	**Mother scores** **Child scores** **50%** positive **40%** very positive **50%** neutral **60%** positive **100% time spent in shared attention** **Quality of relationship** They both appeared to be very attached to each other. **Reciprocity between mother and child** Excellent reciprocity between this mother and her daughter.

10.1 Detachment

The difficulties experienced by mothers with their children's reciprocal interaction and communication resulted in the majority of them finding it problematic to establish and maintain a connection with their children. Five of the mothers considered the interactions to be very much one-sided in relation to them making most, if not all, of the effort to interact. Four mothers expressed difficulties in maintaining the one-sidedness of their relationship. This was reflected in the *early* PSI scores for **attachment** where four mothers reported significant difficulties with attachment during the period of assessment. Their scores ranged between the 75th and the 97th percentile. One mother (Delia), although she equally referred to difficulties in forming a connection with her child, had a PSI score at the 25th percentile.

The **reinforces parent** scores during this period were all between the 90th and 100th percentile and reflected the issues these mothers faced with reciprocity and feedback from their children, as expressed by Jill:

> *'she's not communicating and I'm quite frankly going potty here, I was going ballistic because she wasn't speaking to me. She wasn't looking at me and I didn't know what she wanted'* (Jill, NVivo line number 414)

Delia, however, stated that although it was difficult to make that connection she never let it 'get her down':

> *'It would take a while to get a connection between us but I never used to get down or anything like that, I suppose in a way I probably had a bit more patience'* (Delia, NVivo line number 238)

Unlike the other mothers, the mother from the unusual case, when asked whether she had ever experienced any difficulties bonding or connecting with her daughter, stated that she had always had a strong bond:

'we were very close' (Gail, NVivo line number 480)

'I think if I had not had that strong relationship with her from the start then yes I would possibly have thought that' (Gail, NVivo line number 421)

This was also reflected in her **attachment** score from the PSI which was at the 25th percentile.

10.2 Rejection and failure

The perception by five of the mothers was that they had failed as a mother. They considered their children's difficulties were in some way related to their ability to parent:

'It was an awful time because there was denial, there was deep sadness and I thought it's me because I felt such a failure, I felt like I'd failed' (Jill, NVivo line number 274)

Two mothers explicitly stated that mothers should know instinctively what their children want, and being unable to do so was a reflection of their failure:

'As a parent you should know what they want without them sort of telling you. It's upsetting because you know it's your son, your child, you should be able to communicate with them' (Jane, NVivo line number 203)

One mother talked about how the rejection she experienced resulted in heartbreak for her, and how this reinforced her sense of maternal inadequacy:

'Heartbroken, because this is my son and he doesn't know that he is my son and he doesn't care that he is my son and I will never have the relationship with him that I want to have. He is never going to be the kind of child who will fling his arms around me and share something wonderful, because he just ignores me and it is never going to be any of that. So just heartbroken, absolutely heartbroken' (Sally, NVivo line number 181)

Jill described the heartbreak experienced due to the lack of interaction from her child:

> *'The fact that you can only begin to understand when a child that you've wanted so much does not interact with you the way you thought she would then that is heartbreaking, it's just heartbreaking'*
> (Jill, NVivo line number 795)

10.3 Unsure of love

The need and desire to be loved by one's child was a consistent common thread felt by five of the mothers. All of the mothers, except the mother from the unusual case, were unsure whether their children loved them because they did not articulate or demonstrate their love. As their children did not maintain any meaningful and loving eye contact the mothers felt used as a 'tool':

Jane talked about being desperate to be told by her son that he loved her:

> *'I would desperately love for him to turn round and say mummy I love you'* (Jane, NVivo line number 206)

Sally described how she saw no love in her son's eyes:

> *'He would look at me out of necessity, but there wasn't really any love in his eyes or any emotion really. He would look at me then, and I would look back at him wanting to feel that little sparkle of love. I can't tell you mum, but I'm here and I'm your son and I love you and I didn't get that, which was horrid, and I searched for it and I tried for it….'* (Sally, NVivo line number 143)

Furthermore, Delia described her difficulties in interpreting her child's signals, and how this could lead her to feeling used simply as a means to meet Jake's basic needs, rather than a demonstration of affectional bonds:

> *'I don't know what he's feeling, you don't know if he really wants me for me or if he just wants me to get him a drink'* (Delia, NVivo line number 395)

The mother from the unusual case, however, was in no doubt of the fact that her daughter loved her, despite the fact that she did not explicitly express this in words:

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'I know that she loves me because I see it in other ways' (Gail, NVivo line number 424)

Three of the mothers described not feeling as much love as they believed they should have for their children due to the lack of interaction and feedback. One expressed how she 'disliked' her child because she did not interact. This lack of connection and negative emotions magnified mothers' feelings of failure and of not being a 'proper mother', because 'proper mothers' love their children no matter what. This confusion as to whether they loved their children therefore appears to have stemmed from the fact that they themselves did not feel loved.

Jill talked about the detachment and the dislike she felt:

'There was a detachment and I didn't feel like a proper mum. I didn't feel like I knew I loved her… I did love her but I didn't think she loved me, I thought I knew I loved her but I didn't like her' (Jill, NVivo line number 465)

Sheila talked about how during the time of the assessment and diagnosis she did not feel as much love as she does now:

'At the time I didn't feel as much love as I do now' (Sheila, NVivo line number 669)

In contrast the mother from the unusual case knew from the outset that her daughter wanted her for who she was and as a consequence felt loved:

'I knew that she needed me' (Gail, NVivo line number 595)

'I know that she loves me because I see it in other ways' (Gail, NVivo line number 424)

10.4 Breaking down barriers

The successful introduction of the augmentative communication system PECS with the five non-verbal children resulted in these children initiating an

interaction with their mothers in order to exchange a symbol or photograph. Although acknowledging that this was a function used by their child in order to get something, it nevertheless promoted the initiation of an interaction and communication between the child and his/her mother. This resulted in the mother feeling more positive towards her child:

> *'He is more interactive with me and I am with him. I just feel a lot better about it. I feel a lot better about my relationship with him'* (Sheila, NVivo line number 658)

> *'I didn't know how to reach her and this was like I'd been given this tool where she had to come to me. She had to bring me that sentence strip, and actually interact with me if she wanted something. So in that way yes it broke down barriers with me'* (Jill, NVivo line number 474)

10.5 Believing that she is loved

The desire to be loved by their children was a pervasive emotion experienced by all of the mothers. In order to feel loved their children had to demonstrate in some way, either by an interaction or a communication, that they wanted to be with their mothers. Once the children began to interact and communicate with their mothers, using the PECS, this resulted in them feeling needed, which demonstrated their children's love for them. For example Delia talked about being wanted as a mother rather than just someone to 'get things':

> *'I knew he wanted to come to me. It's like, I felt I was needed, because sometimes you feel you're just someone there who, you know to fetch things. Sometimes you do feel I don't know what he's feeling, you don't know if he really wants you for you, or if he just wants me to get him a drink. But now I know myself that he wants me for me because he's always wanting to hug me and be with me and stuff like that and it's just something I know myself. I know he wants me for me now'* (Delia, NVivo line number 392)

Sally described her child imitating her saying 'I love you' and although she understood this was simply an imitation, nevertheless it made her feel loved:

> *'The massive shift to the present day is that he now looks at me and I'll say I love you, and he will mimic back because he knows that's what we say, but I know he loves me'* (Sally, NVivo line number 383)

Therefore, although the children were unable to communicate spontaneously, either verbally or using PECS, that they loved their mothers, the mothers interpreted other behaviours as signs of their children's love for them:

> *'It was a sudden realisation that she wants to be near me now'* (Jill, NVivo line number 601)

> *'He does now sit on my knee and put his arms around me and I suppose that is his way of saying it'* (Jane, NVivo line number 212)

This was endorsed by the fact that the mother from the unusual case never expressed any doubts about being loved by her daughter, and felt from the outset that her daughter loved and needed her because she could express it verbally:

> *'I knew that she needed me'* (Gail, NVivo line number 595)

These positive emotions were demonstrated in the *later emotions* PSI **attachment** scores which reflected the mothers' emotions post assessment and diagnosis. The **attachment** scores ranged between the 50th percentile and the 3rd percentile, therefore reflecting a more positive perception of their attachment with their children. Interestingly, there was very little change in the **reinforces parent** scores between the *later emotions* PSI scores, which reflected emotions post assessment, and the *early emotions* PSI scores, which reflected emotions during the assessment. The possible reasons for this are discussed in chapter 14.5, p.292.

10.6 Becoming a proper mum

The concept of being a 'proper mum' stems from the fact that four of the mothers only felt as though they were fulfilling their role as a mother if their children interacted with them. Therefore once their children did start to interact they perceived this to mean that they were now a 'proper' mother:

> *'It made me feel that she'd seen me that I was here as well. You know it wasn't just about dad and her grandfather and grandmother. I was here as well, you know, and that made me feel like a proper mum'* (Jill, NVivo line number 449)

All of the mothers talked about being needed, and conceptualised a 'mother' with being able to act upon requests made by their children. Therefore once their children were able to communicate their needs, the mothers felt as though they fulfilled their role when they met those needs:

> *'It is not the words at all it is just him putting his point across and me being able to make that a reality for him because that's what mums do. They make stuff, they fix stuff and he's now got the means to tell me things and I am his mum and I can fix that. I can do that for you'* (Sally, NVivo line number 217)

One mother also described no longer feeling used as a 'tool' when her child started to interact with her, and how she felt needed as a mother:

> *'But now I know myself that he wants me for me because he's always wanting to hug me and be with me and stuff like that and it's just something I know myself. I know he wants me for me now'* (Delia, NVivo line number 397)

Delia also stated, however, that although her son was able to interact with her she did not need this to make her feel like a better mother, but it did make her feel better because she was able to offer him safety and comfort:

> *'It didn't make me feel like I was a better mother, because he was wanting me and stuff like that. I think it just made me feel good because he felt that he could come to me and he knows that he felt safe with me'* (Delia, NVivo line number 422)

The results from the **reinforces parent** scores from the PSI remained high when the *later emotions* PSI was completed, with very little change from the *early emotions* PSI except participant 1 (Jill) (see figure 10.2). This indicated that the mothers may still have found the feedback and reciprocity from their children limited. The reason for this may lie in the results from the child scores from the mother-child interaction. The accumulative scores from all children indicate that the majority of the behaviours were negative (see figure 10.4).

It is therefore possible that the children continued to have considerable difficulties with their interaction and communication with their mothers, which the mothers recognised and reflected in their reporting in **reinforces parent** in the PSI. However, because the children's interaction and communication had improved compared to what it had been initially, they were able to rationalise this and their perception of their relationship with their children improved.

Figure (10.2) Reinforces parent scores from early and later emotions on the PSI
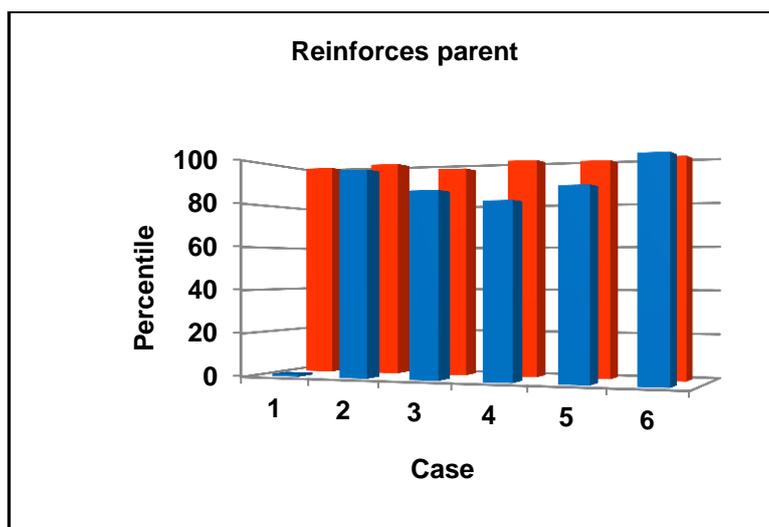
Figure (10.3) Attachment scores from early and later emotions on the PSI

Early emotions

Later emotions
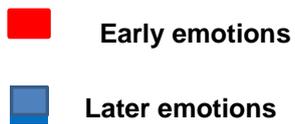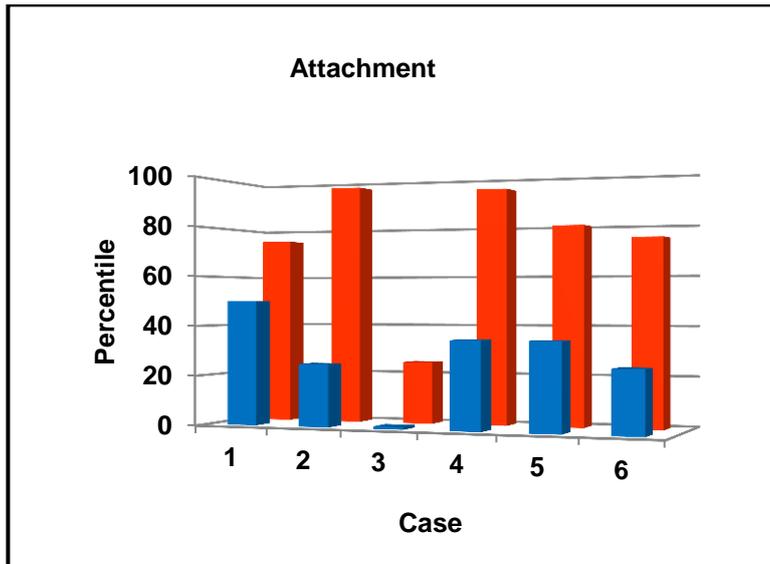
Figure (10.4) Accumulative child scores from mother-child interaction
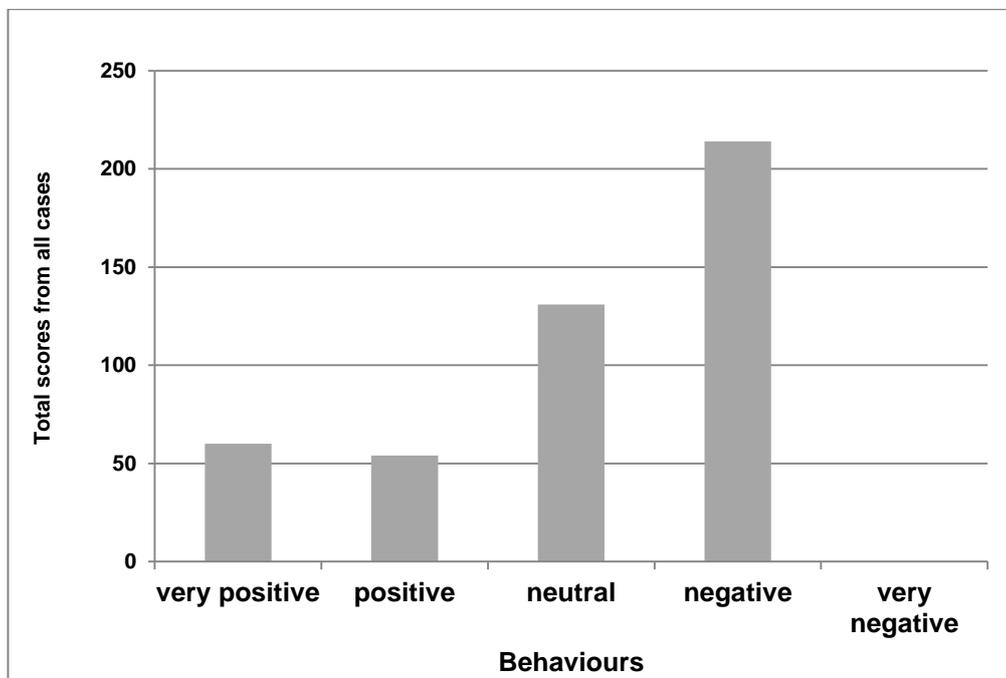
10.7 Key findings from dynamic interactions

The following are the key findings from the dynamic interaction dimension:

➤ Difficulties with their children's reciprocal interaction and communication resulted in the majority of mothers finding it problematic to establish and maintain a connection with their children.

➤ The perception by five of the mothers was that they had failed as a mother as they considered their children's difficulties in some way related to their ability to parent.

➤ Five of the mothers were unsure whether their children loved them because they did not articulate or demonstrate their love.

➤ Augmentative communication system resulted in non-verbal children initiating an interaction with their mothers.

➤ Interaction and communication with their mothers resulted in them feeling needed, which demonstrated their children's love for them.

➤ Interaction was perceived to mean that they were now a 'proper' mother.

10.8 Conclusion

This chapter gave a detailed analysis of the dimension the *dynamic interaction,* and included the theme the **reciprocal bond** which encompassed the attachment of the mothers to their children as well as the reciprocal nature of the relationship. The six sub-themes were discussed in detail. The following chapter will discuss in depth the function of the mother within the dynamic interaction and will encompass two themes: the **contradiction of emotions** and **craving normality**.

CHAPTER ELEVEN

FUNCTION OF THE MOTHER WITHIN THE DYNAMIC INTERACTION

This chapter comprises the dimension *the function of the mother within the dynamic interaction* and encompasses two themes - **contradiction of emotions** and **craving normality**, and focuses upon the mothers' emotions and affect during and after assessment and diagnosis.

The theme **contradiction of emotions** consists of five sub-themes and **craving normality** consists of two sub-themes, all of which are represented in figure (11.1) and the cross-case analysis matrix is represented in table (11.1)

Also included were:

Observation: The mother's **affect** scores.

PSI: Depression, child mood and **total stress.**

Figure (11.1) Function of mother within the dynamic interaction
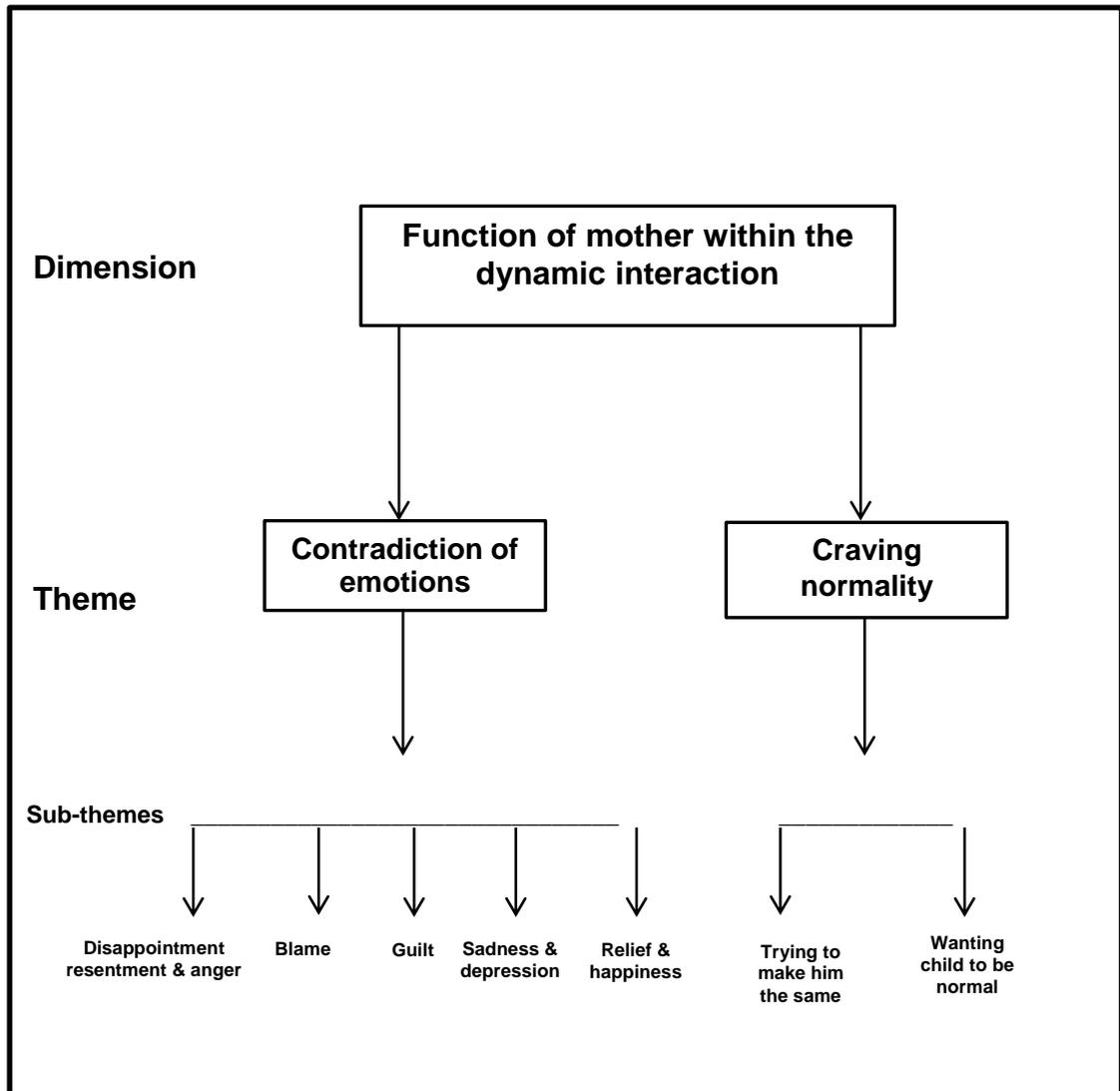
Table (11.1) Cross-case analysis matrix for the function of mother within the dynamic interaction

Cases	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Jill & Alison (1)	**Disappointment** because her daughter would not interact with her **Anger** directed at her daughter for causing her to feel disappointed **Resentment** at the loss of what might have been **Guilt** for not being a proper mother **Sadness** because her child would not interact	Depression **100**th percentile Child mood **100**th percentile Total stress **100**th percentile	**Relief** that professionals were offering support **Happy** when her daughter interacted with her and no one else	Depression **15**th percentile Child mood **90**th percentile Total stress **40**th percentile	Mother's affect score: **4**
Sally & Duncan (2)	**Disappointment** for herself as well as for her child **Resentment** for what she had to give up in her life **Guilt** because she did not love him **Sadness**: mother felt sad most of the time during the early years **Depression** was a feature of her life for several years because she couldn't bear to think about the future	Depression **100**th percentile Child mood **100**th percentile Total stress **100**th percentile	**Relief** when she realised it wasn't her fault **Happy** when he interacted with her using PECS for the first time	Depression **91**st percentile Child mood **90**th percentile Total stress **99**th percentile	Mother's affect score: **5**
Delia & Jake (3)	**Disappointment** for her child but not for her Wanted him to communicate and **be like** other children	Depression **82**nd percentile Child mood **90**th percentile Total stress **96**th percentile	**Easier interaction improved mood:** mother's mood improved when the interaction from her son became more natural	Depression **35**th percentile Child mood **95**th percentile Total stress **72**nd percentile	Mother's affect score: **3**

Sheila & Jack (4)	**Disappointmen**t that he was not like other children and that it was her fault **Guilt** for not being understanding of his autism **Sadness** because she couldn't communicate with him	Depression **97**th percentile Child mood **96**th percentile Total stress **99**th percentile	**Relief** because during the EarlyBird course began to realise it was not her fault **Happy** when he wants to interact with her Accepted him for who he was over time	Depression **75**th percentile Child mood **50**th percentile Total stress **61**st percentile	Mother's affect score: **4**
Jane & Tom (5)	**Disappointment** with the diagnosis and therefore the implications for the future **Blaming** child for not making the effort: this mother felt that her child was purposely choosing not to make an effort to communicate or interact with her **Guilt** for feeling disappointed **Depression** was a feature of her life for many years	Depression **100**th percentile Child mood **60**th percentile Total stress **99**th percentile	**Relief** due to support offered by professionals	Depression **96**th percentile Child mood **85**th percentile Total stress **96**th percentile	Mother's affect score: **3**
Gail & Emily (6)	**Resentmen**t at having to carry out tasks which she felt were over and above her maternal duties	Depression **35**th percentile Child mood **100**th percentile Total stress **96**th percentile		Depression **30**th percentile Child mood **99**th percentile Total stress **94**th percentile	Mother's affect score: **4**

11.1 Contradiction of emotions

The theme **contradiction of emotions** relates to the mothers' negative and positive affect.

11.1.1 Disappointment, resentment and anger

Disappointment, resentment and anger were common emotions expressed by most of the mothers. These emotions often resulted in feelings of guilt as they believed that no mother should experience any of these emotions and they should accept their children for who they are.

Five of the mothers described experiencing some type of disappointment. Some mothers yearned for a child without any disability, and some believed that having a child with autism would be a burden for the rest of their lives. They were also disappointed about their children's lack of ability to interact and communicate. For three of these mothers this resulted in feelings of 'anguish' and 'guilt'. Jane talked about wishing she did not have a child with a disability, and feelings of self-hate as she believed she should not be disappointed:

> *'you feel disappointed in your child because they have got these disabilities and then you hate yourself for thinking that and you feel that you should not be disappointed in your child so you put that to the back of your mind'* (Jane, NVivo line number 219)

Another form of disappointment related to mothers' concern about how their children would never achieve what 'normal' children would, and how they may suffer from difficulties all of their lives. This disappointment for their children appeared to be due to the perceived difficulties their children may face throughout their lives with prejudice and stigma:

> *'He is going to be judged for his whole life and in certain circumstances where people do not understand him, they will make assumptions and that breaks my heart'* (Sally, NVivo line number 449)

Delia and Sally both explicitly denied feeling disappointment for themselves; however, they did implicitly state that they felt disappointment for their children:

> Q*:* 'Did you feel disappointed?'
>
> *'Not really no, I always knew there was something wrong, I knew it wasn't his fault. So, I don't feel disappointed, but if I had the choice I would have chosen for him not to have autism, not for me but for him'* (Delia, NVivo line number 458)
>
> *'I'm not disappointed for me, disappointed isn't even a good word, devastated for him, because I don't want it for him'* (Sally, NVivo line number 179)

Another described feeling disappointed for herself and her child:

> Q: 'Did you feel disappointed?'
>
> *'Yes, for him as well as for me, but yes, because life was going to be crap pretty much'* (Sally, NVivo line number 177)

However, this mother also indicated how the whole experience had given her a clearer perspective on life, and had made her a 'better person':

> *'It's made me a better person and it has given me a better perspective on life and what is important'* (Sally, NVivo line number 458)

Resentment was experienced by three mothers. This resentment was fundamentally related to their children not giving them what they perceived other mothers have and what other mothers may experience in the future:

> *'yes I did resent her, I did, and it's when you think about you know, she will never get married you know, I will never have what other mothers have. Hideous feelings'* (Jill, NVivo line number 1043)

Sally expressed resentment for not being able to fulfil her dreams in life:

> *'I would still be in Dubai, if it wasn't for him'* (Sally, NVivo line number 756)

Another reason for resentment was expressed by Gail, who felt burdened by the tasks which she may not have had to do if her daughter did not have autism:

> *'I slept with her every night and I never had a night off and I resented that'* (Gail NVivo line number 316)

Jill disclosed anger due to her long-awaited child not meeting her expectations:

> *'I was really angry actually at her. That was wrong you know to be angry at her it wasn't her fault, but I was angry at her'* (Jill, NVivo line number 799)

11.1.2 Blame and guilt

Blame and guilt appeared to go hand in hand, and often when mothers discussed their experiences of guilt they would state that it was because they were to blame. Although rationally they knew that they were not to blame for their children's difficulties, they nevertheless felt guilty for their children's problems. This is also related to the concept of failure as discussed in chapter 10.2, p. 230.

Gail and Sheila felt that they were in some way to blame for their children's difficulties with behaviour and lack of interaction and communication. These mothers perceived their children's issues resulted from some 'mistake' in their mothering skills:

> *'I took the blame for her not doing what she should do'* (Gail, NVivo line number 287)

> *'I thought it was my fault I thought I was doing something wrong'* (Sheila, NVivo line number 352)

One mother compared her abilities to those of her husband and felt guilty because she did not feel as though she had the same skills as he did:

'I did completely and utterly reproach myself and I thought, well, you don't even know how to play with her. I just really punished myself. I did cos I thought it was me cos my husband plays with her, why can't I' (Jill, NVivo line number 519)

Two of the mothers also felt that their children were intentionally choosing not to communicate or interact with them, and therefore blamed their children for the lack of interaction between them:

'he just wasn't trying to interact with us or trying to get our attention or trying to ask for anything' (Jane, NVivo line number 106)

As previously discussed, guilt was related to the lack of love that mothers felt towards their children. Considerable feelings of guilt were experienced by the four mothers who perceived themselves not to be a proper mother and to have caused some of the difficulties:

'I felt guilty for not being a proper mother' (Jill, NVivo line number 810)

'so, back then, there was no love and a lot of guilt as well, because obviously I thought I had made him that way' (Sally, NVivo line number 363)

Sheila expressed how she would lose patience with her son due to not understanding his behaviour, leaving her feeling guilty:

'I just think I should be a bit more understanding with him, it's only when I have shouted and made him go up to his room that I then think, it's that feeling when I calmed down I think why did I do that, he doesn't understand what he's done and I'm just ranting off and I feel very disappointed in myself. It's not his fault it's mine'.(Sheila, NVivo line number 544)

11.1.3 Sadness and depression

Sadness and depression appear to be inextricably linked. When a mother talked about sadness she also often talked about feeling depressed. Two mothers were treated for clinical depression and suggested that it was directly linked to

having a child with autism. Three of the mothers described their sadness and depression as being a direct result of being unable to communicate with their children:

> *'I was so sad, I was so desperately sad, and I didn't want to be that way. I wanted to be happy and you know I wanted to be able to play with her and get her to play with me'* (Jill, NVivo line number 944)

> *'It's quite sad really when you feel you should be able to communicate with your child even without speech. You know you should be able to pick up on what they are trying to tell you without communicating verbally but he just doesn't show any of that'* (Jane, NVivo line number 152)

Sally spoke of feeling overwhelmed by the enormity of the situation she found herself in:

> *'everything was just sadness'* (Sally, NVivo line number 496)

> *'Lots of antidepressants* (laughing) *no, honestly three years that's the only thing that got me through the day for years and I tried stopping taking them and then the desperate sadness and gravity of stuff I had to do to just to make it through the day was too much, just too much'* (Sally, NVivo line number 653)

The *early emotions* PSI scores for **depression** were all between the 82nd and 100th percentile, except for the unusual case which was only at the 35th percentile. In the *later emotions* PSI two mothers had **depression** scores which remained high between the 96th and 91st percentile, whereas the others were between the 75th and 15th percentile. Both of the mothers whose scores remained high post interview were the mothers who had been treated for clinical depression.

11.1.4 Relief and happiness

Relief and happiness was expressed by four mothers, often for different reasons. Three mothers expressed relief at having a diagnosis as it provided a reason for their children's difficulties and removed their sense of blame for causing these difficulties:

> *'But I was more relieved because then I knew that was definitely the reason why he was the way he was, because if they hadn't diagnosed autism it would be like well, what's wrong with him and then we would have to go through more you know, like not tests but assessments and stuff like that, but I was relieved because at least then I knew. I knew why he was the way he was.* (Delia, NVivo line number 690)

> *'Well I just thought I can let myself off the hook a bit with Emily because I thought yes she is different'* (Gail, NVivo line number 295)

Another source of relief was expressed by four of the mothers and related to the support that they received from professionals. This was often expressed in terms of relief that they were able to hand over some of the burden to someone else:

> *'I knew that there is a support network, a support network there for me as well, and it was that support I hadn't had. I just felt well relief and I felt relieved that I was in the right place'* (Jill, NVivo line number 351)

Relief was also expressed by Sheila in relation to her understanding of autism and the dawning realisation that it was not her fault:

> *'The EarlyBird course, that was like an eye-opener, and it wasn't me it wasn't me. That's what it felt like, that's what I needed. The worry was sort of taken away from me'* (Sheila, NVivo line number 267)

Happiness was expressed by all mothers except the mother from the unusual case. This positive emotion was related to their children initiating an interaction or a communication and, when questioned about how they felt when their

children initially interacted with them to exchange a PECS symbol, two mothers

stated that it made them happy because they communicated like other children:

> *'Oh it was great, it was brilliant you know it was really good. I just felt so proud, and as I said it's like Jake is doing things what children do every day and it's probably nothing to them, but when he does an achievement like that. You know it makes me really really happy'*
> (Delia, NVivo line number 382)

It appeared, however, that the interaction had to be specifically with them and

no one else:

> *'Happy, I'm happy that he is like that, that he is wanting to interact with me and to play, wanting me to do things with him. I'm absolutely thrilled and made up that he is like that'* (Sheila, NVivo line number 210)

> *'she'd bring it to **me** and she'd come over and communicate with **me** and it was marvellous it was like a revelation almost'* (Jill, NVivo line number 422)

One mother talked about her joy that her daughter would interact with her rather

than her husband following a Portage session (Portage is a home-visiting

educational service for pre-school children with additional support needs and

their families):

> Q: 'What was it about the play that made you happy, that made the difference?'

> *'The communication afterwards that she would want to continue to play those games, and she would seek out the person that knew how to play that game and I was privy to that. She knew it was me and not him'* (Jill, NVivo line number 960)

11.2 Craving normality

This theme relates to the mother's desire for her child to be like other typically

developing children.

11.2.1 Wanting child to be normal

The desire for their children to be 'normal' like other children was expressed by three mothers, and when they observed their children with others it appeared to exacerbate this emotion. One mother talked about how hard it was watching her child with others:

> *'I would love him to just be able to get in on a little group and just run around and do the things that the rest of the kids do. I mean he will join in now and again but most of the time he stands on his own, all you want is for them to be normal or able like other children, whatever the word is'* (Jane, NVivo line number 227)

For a child to be 'normal', however, also involved communicating like other children.

11.2.2 Accepting him for who he is

Although two of the mothers desperately wanted their children to be like other children, they both felt that time had allowed them to accept their children for who they were:

> *'I think it's just acceptance of the way he is over time'* (Sheila, NVivo line number 660)

The PSI domain **child mood** reflects the perception the mother has of her child's affect, and *early emotions* scores in five mothers were between the 96th and 100th percentile, which included the unusual case. Jane's scores were the only exception and were on the 60th percentile. Interestingly, the *later emotions* scores, including Jane's, remained high and were between the 85th and 95th percentile, except Sheila's which was at the 50th percentile. Again, this may be related to the mothers' perceptions that the children continued to have significant difficulties with interaction and communication, but they were more

reconciled to this and did not necessarily regard it as a reflection on their parenting, demonstrated in their *later emotions* **depression** scores post-interview.

The *early emotions* **total stress** score for all six mothers was exceptionally high and ranged between the 96th and 100th percentile, reflecting the strain that they felt during this time. Two mothers who had received treatment for clinical depression had high scores in the *later emotions* PSI, whereas the others had scores between the 72nd and the 40th percentile. The mother from the unusual case also continued to have a high **total stress** score, again possibly reflecting the fact that she had received no professional support or autism-specific strategies.

Figure (11.2) Maternal depression scores from the PSI
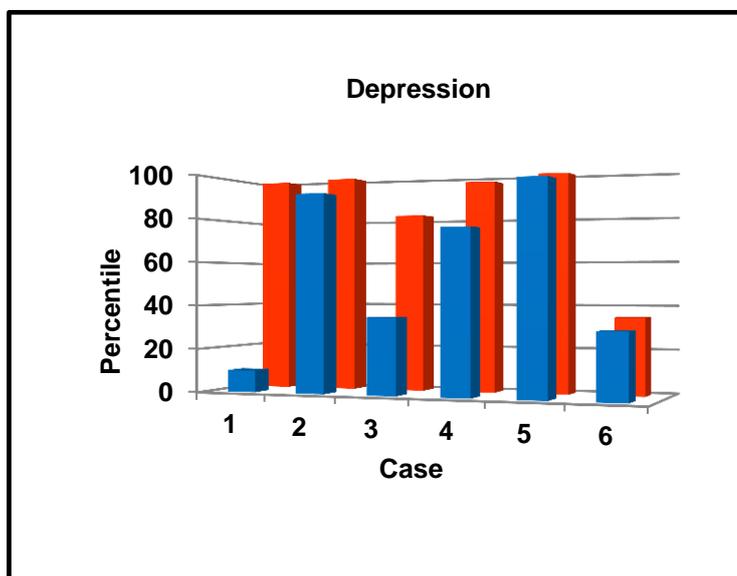
Figure (11.3) Child mood scores from the PSI

Child mood

Early emotions
Later emotions
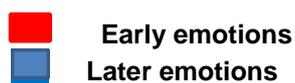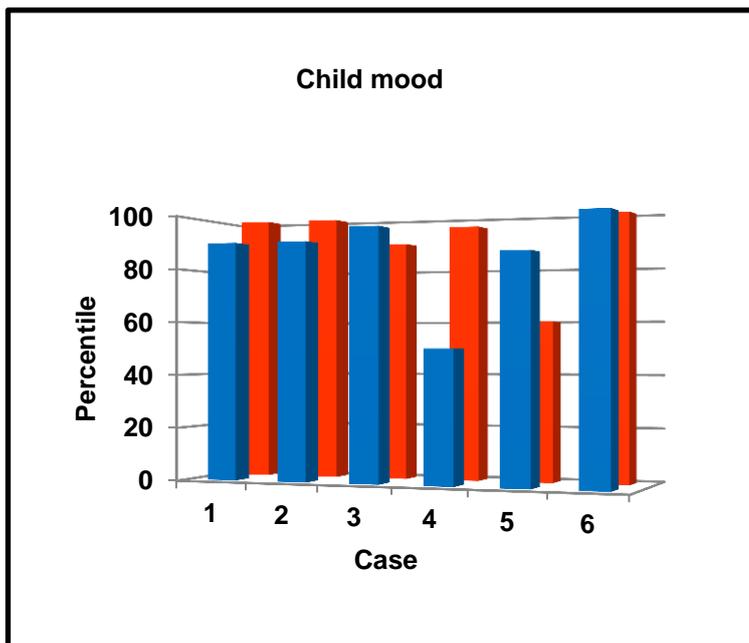
11.3 Key findings from function of mother within the dynamic interaction

- ➤ Disappointment, resentment and anger often resulted in feelings of guilt.

- ➤ Sadness and depression due to being unable to communicate with their children.

- ➤ Relief and happiness derived from diagnosis, professional support and an increased understanding of autism.

- ➤ Mothers craved their children to be the same as other children.

11.4 Conclusion

This dimension reflected the mothers' struggles with contradictions in their emotions which ranged from feelings of anger to guilt, sadness and depression. Most mothers went on to express happiness and relief when their children were

able to communicate and interact with them. Several mothers also struggled with wanting a child who was 'normal', eventually arriving at an acceptance of the disability and being able to accept their children for who they are.

In the following chapter the dimension **personal qualities** is presented. This dimension encompasses the theme of 'being up to the job'.

CHAPTER TWELVE

PERSONAL QUALITIES

This chapter comprises the dimension the *personal qualities,* and encompasses the theme **being up to the job**, which relates to the concept of the responsivity or synchrony by the mother in her interaction and communication with her child. These concepts go hand in hand with the theme **a state of transformation** (chapter 13) and should be considered in conjunction with this theme.

Also included were:

Observation: Mother's responsiveness and synchrony when using the specific strategies learnt on the EarlyBird course and from the PECS training.

PSI: Competence scores.

The theme **being up to the job** consists of 3 sub-themes all of which are represented in figure (12.1) and the cross-case analysis matrix is represented in table (12.1)

Figure (12.1) Personal qualities
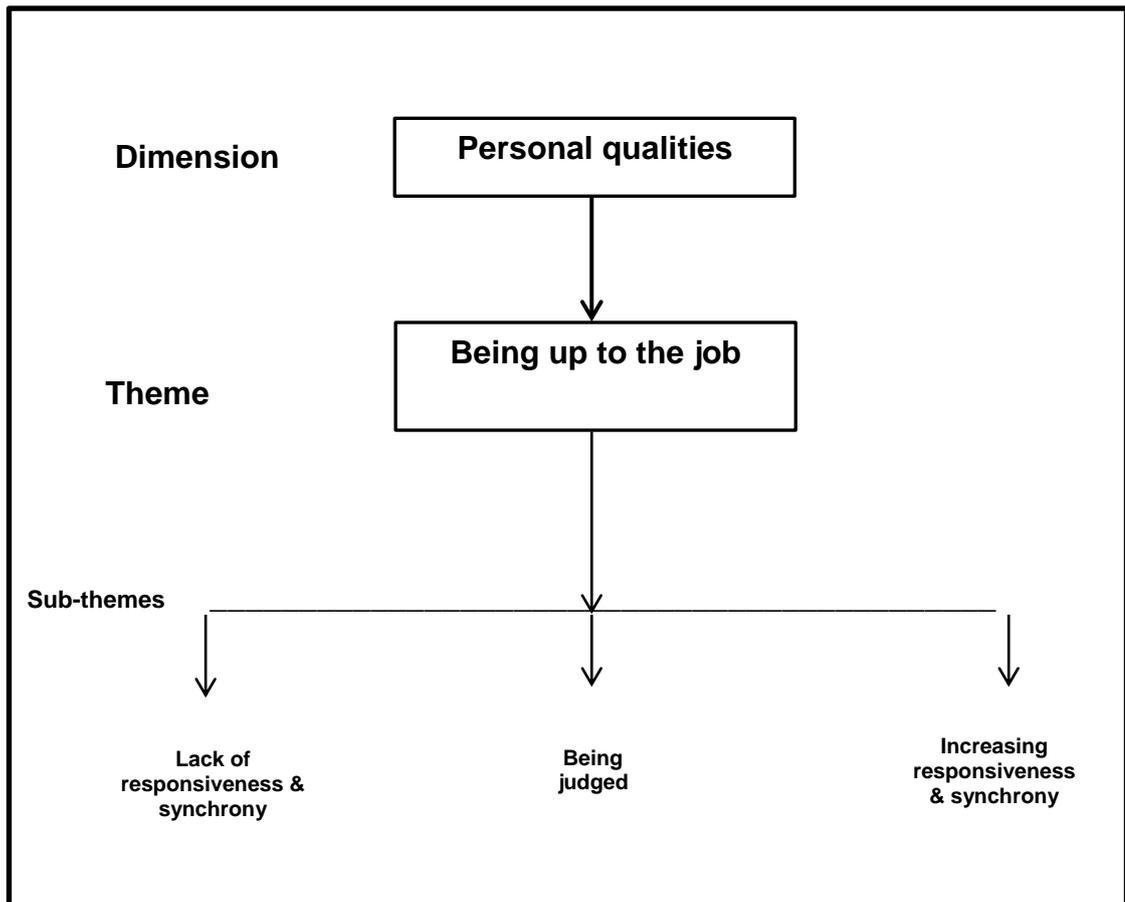
Table (12.1) Cross-case analysis matrix for personal qualities

Cases	Interview (Negative emotions)	Pre-interview PSI	Interview (Positive emotions)	Post-interview PSI	Mother-child interaction
Jill & Alison (1)	**Lack of responsiveness & synchrony:** reproaching herself because she didn't know how to interact with her daughter and felt it was her fault.	Competence **100th** percentile	**Increasing responsiveness & synchrony:** gained confidence that she never thought she would have, once autism-specific strategies were introduced.	Competence **35th** percentile	**Observations re competence made during the video observation:** appeared confident during most of the session; however, occasionally her daughter refused to cooperate at which point the mother became slightly anxious.
Sally & Duncan (2)	**Lack of responsiveness & synchrony:** lack of understanding of how to manage him and interact with him.	Competence **100th** percentile	**Increasing responsiveness & synchrony:** felt more confident as a mother because he chose to approach her.	Competence **91st** percentile	**Observations re competence made during the video observation:** mother appeared to be very competent and confident with her interaction skills, and in managing her child.
Delia & Jake (3)		Competence **45th** percentile	**Increasing responsiveness & synchrony:** mother didn't feel as though she needed any interaction in order to feel like a confident mother.	Competence **25th** percentile	**Observations re competence made during the video observation:** mother used a warm facial expression and appeared to be very relaxed and confident. She was competent in her use of communication strategies to meet his needs.
Sheila & Jack (4)	**Lack of responsiveness & synchrony:** lacking in confidence when interacting and communicating with her son. She was frightened to get it wrong.	Competence **96th** percentile	**Increasing responsiveness & synchrony:** mother's confidence increased when her child started interacting with her.	Competence **35th** percentile	**Observations re competence made during the video observation:** appeared quite confident although not sure she was aware of how much she led the interaction.

Jane & Tom (5)	**Lack of responsiveness & synchrony:** unable to understand how to interact with her son. **Being judged:** very concerned about what other mothers were thinking about her ability to parent her son.	Competence **40th** percentile	**Increasing responsiveness & synchrony:** confidence increased with increased understanding of autism and interaction.	Competence **60th** percentile	**Observations re competence made during the video observation:** mother appeared anxious and she found it difficult to implement strategies learnt on EarlyBird.
Gail & Emily (6)	**Lack of responsiveness & synchrony:** this appeared to stem from not understanding the diagnosis and therefore led to frustration.	Competence **60th** percentile	**Increasing responsiveness & synchrony::** better understanding of how to manage her daughter helped to improve mother's confidence.	Competence **45th** percentile	**Observations re competence made during the video observation:** appeared to be very confident when interacting with her daughter. She allowed her daughter to lead the game but did take control back again when her daughter appeared to be trying to take control.

12.1 Lack of responsiveness and synchrony

A lack of responsiveness and synchrony that the mothers experienced with their children appeared to result in a lack of confidence. This was experienced when mothers perceived themselves as either unable to manage their children's behaviours, or to communicate and interact with their children. This lack of confidence resulted in decreased competence or responsiveness, as the strategies that they used in order to interact with and manage their children were often ineffectual. Lack of confidence was experienced by five out of the six mothers, which included the mother from the unusual case. Interestingly, the mother (Delia) who did not express any lack of confidence remained determined throughout the interview that she was not deficient in competence or confidence in any way, and was adamant about her ability to parent her child. She also suggested that the specific autism strategies were not necessary to help her feel confident in her mothering skills:

'It didn't make me feel like I was a better mother' (Delia, NVivo line 422)

Delia did, however, go on to state that she probably felt confident because the autism-specific strategies had been introduced when her child was very young, and therefore she may not have been as aware of his difficulties as the other mothers may have been. This mother's competence was also confirmed during the observation of her interacting with her child.

One mother described her difficulty and inability to understand what her child wanted:

'Just not knowing what to do, not knowing what the problem was. He was upset, distraught, and I didn't know what to do' (Sally, NVivo line 235)

Sheila spoke of being afraid to manage her child in the 'wrong way':

Probably very strained really, very tentative with him, I was a little afraid. I didn't know how to handle him or whether I was doing things right, if it was me was it my fault. (Sheila, NVivo line 659)

Lack of confidence was not necessarily expressed openly by some mothers; however, they did express their inability to carry out certain parenting skills. This resulted in what could be perceived as a lack of responsivity and therefore competence. These difficulties with competence appeared to often be related to the mother experiencing difficulties in communicating with her child, as several of the mothers suggested that they should have known instinctively how to manage their children:

'It's quite sad really when you feel you should be able to communicate with your child even without speech' (Jane, NVivo line 152)

'it's difficult when you think that you are doing something disastrously wrong because your child can't sit there and tell you especially when it comes to feelings' (Jane, NVivo line 204)

'I did completely and utterly reproached myself and I thought, well, you don't even know how to play with her' (Jill, NVivo line 518)

Interestingly, this lack of competence experienced by these mothers appears again to have been related to their perception that it was in some way their fault.

12.2 Being judged

Jane was very concerned about being judged by other parents with regard to her ability to parent her child. This undermined her ability to manage her child and reinforced her belief that she was not a good or a competent mother:

'They make you feel in a lot of ways like you are a bad parent and they make you feel ashamed that you're not doing what you should be doing' (Jane, NVivo line 201)

'I think when Tom is having a bit of a strop you know what other people are thinking about you, especially if they don't realise that he is special needs' (Jane, NVivo line 78)

12.3 Increasing responsiveness & synchrony

Following the PECS and EarlyBird training mothers expressed increased responsiveness and synchrony with their children, leading to enhanced competence. Most of the mothers referred to an increasing understanding of their children's difficulties and of the aetiology of autism. Their sense of competence was also augmented by their increasing awareness of how to interact with and communicate with their children in a manner that was conducive to lessening their children's difficulties. As stated by Jill, her growth in competence led to increased confidence:

'It's really changed me, you know, I do things that I thought I would never do you know outside of the house, anything to interact with Alison. You know to gain that closeness that we have got now, you know that's really unbelievable from me' (Jill, NVivo line 533)

Despite the fact that the mother from the unusual case had not received any autism-specific strategies, she realised that with a better understanding of her daughter's difficulties she herself was better able to cope. The understanding of the implications of her daughter's difficulties appears to have been as a result of receiving a diagnosis:

'there is more of an understanding there. And it is much more a case of how am I going to help with this rather than why the hell is she not listening to me' (Gail, NVivo line 539)

Sheila felt that once her child became more interactive and the interactions were reciprocal this directly impacted on her self-confidence:

Q: Was your confidence helped by the interaction?

'Certainly, yes absolutely you know that I'm getting something back from him is absolutely brilliant, absolutely' (Sheila, NVivo line 676)

The results from the **competence** scores on the PSI (figure 12.2) were considerably higher on the early emotions PSI than they were in the later emotions PSI, indicating that the mothers felt far more competent once their understanding and knowledge of autism had increased and they had been given the skills to interact and communicate with their children. As already mentioned, one mother's score was higher post interview. It is possible that once this mother's knowledge and understanding grew, so did her positive self-critique.

Figure (12.2) Maternal competence scores from the PSI
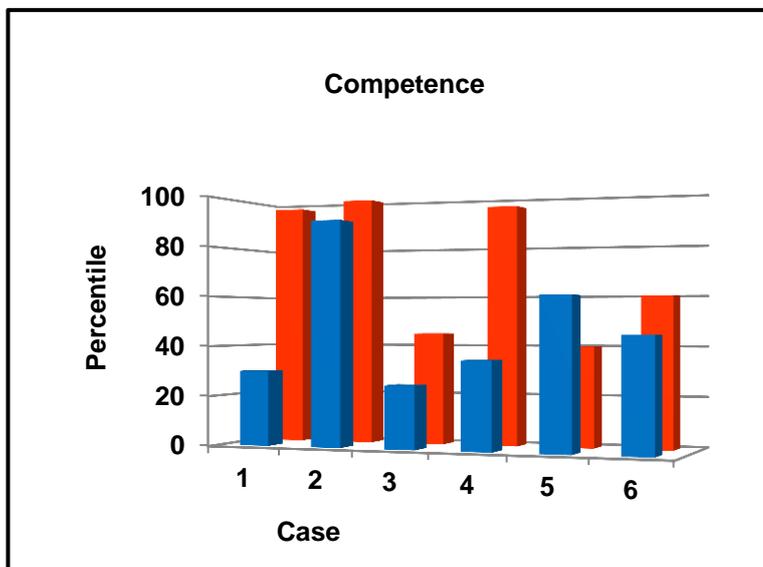
12.4 Key findings from personal qualities

➢ A lack of confidence resulted from a lack of responsiveness and synchrony.

➢ One mother felt judged by other mothers.

➢ Increased understanding of autism and communication/interaction strategies resulted in increased competence and therefore confidence.

12.5 Conclusion

This dimension provided an understanding of mothers' struggles with responsiveness and synchrony, and the effects this had upon their confidence. With their increased understanding of autism and methods of interaction with their children also came an increase in their competence.

In the following chapter the **facilitators and barriers** dimension is presented. This dimension focuses on four themes: 'the challenge of others', 'a precarious alliance', 'a state of transformation', and 'a journey well-travelled'.

CHAPTER THIRTEEN

FACILITATORS AND BARRIERS

This chapter comprises the dimension the *facilitators and barriers* and encompasses four themes – **the challenge of others, a precarious alliance, a state of transformation** and **a journey well-travelled.** It includes the factors which facilitate the relationship that the mother has with her child as well as the barriers to her developing and maintaining the relationship. These include the mother's relationship with her partner and others, the process of assessment, the interventions she and her child received, and finally the diagnosis.

Also included were:

Observation: The scores used from the mother-child interaction include strategies taught during the EarlyBird course and include

- Quality and amount of visual contact and ability to get down to child's level
- Quality and appropriacy of language used by mother
- Quality and amount of gestures and non-verbal clues used to support understanding
- Mother's ability to demonstrate flexibility and creativity to engage her child

PSI: The additional use of the PSI allowed for the exploration of the mother's scores in the **spouse** domain.

The theme **the challenge of others** consists of three sub-themes, **a precarious alliance** has four sub-themes, **a state of transformation** four sub-

themes, and **a journey well-travelled** two-sub themes, all of which are represented in figure (13.1) and the cross-case analysis matrix is represented in table (13.1)

Figure (13.1) Facilitators and barriers
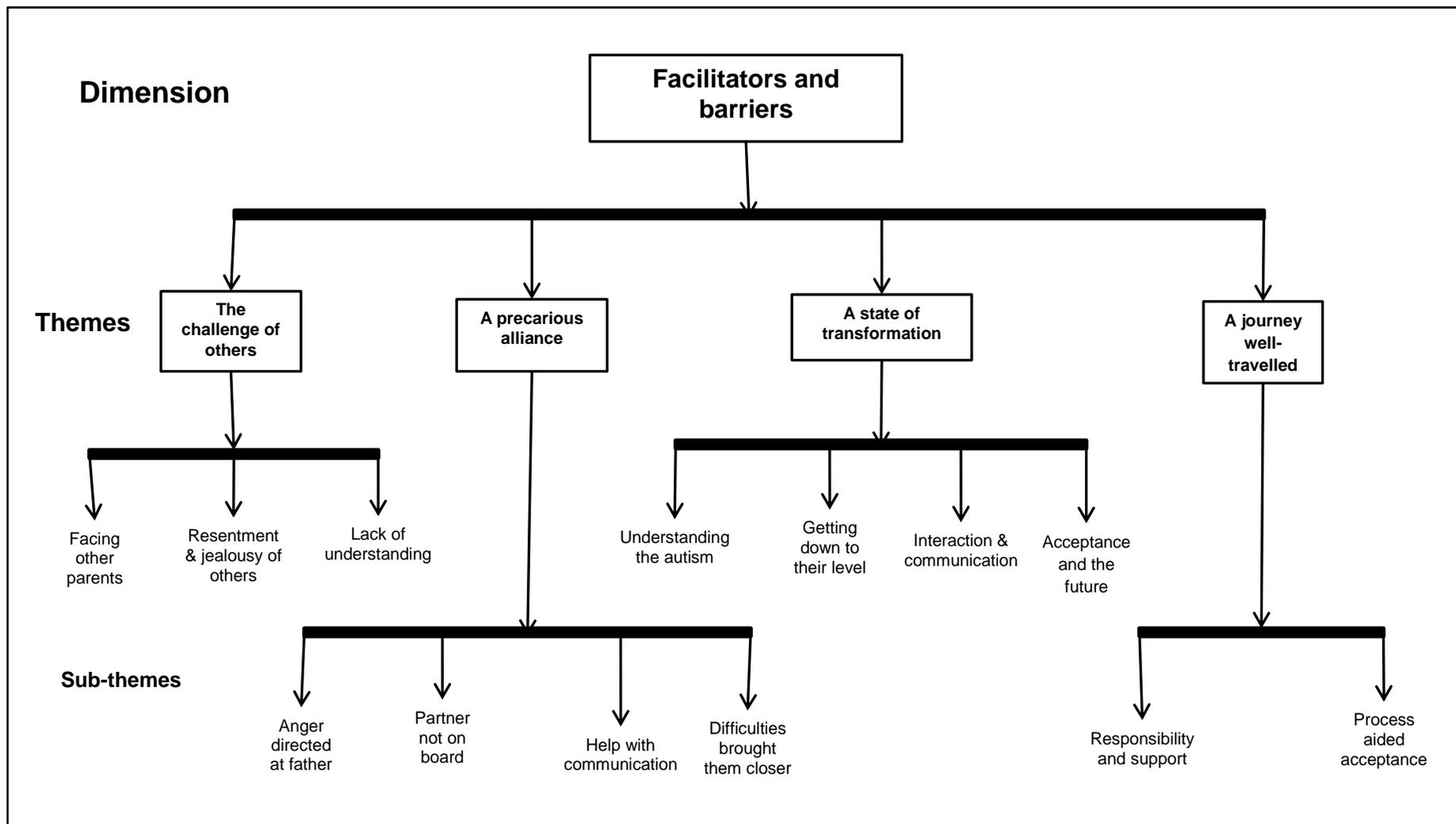
Table (13.1) Cross-case analysis matrix for the facilitators and barriers

Cases	Interview (Negative emotions)	Early emotions PSI	Interview (Positive emotions)	Later emotions PSI	Mother-child interaction
Jill & Alison (1)	**The challenge of others** **Facing other parents:** difficulty facing other parents as she thought she was being judged by them; therefore, she pretended everything was fine. **Resentment & jealousy of others:** mother felt very jealous of other mothers who had children with no difficulties. She also resented other children who she perceived to be 'normal'. **Others' lack of understanding:** some professionals showed a lack of understanding and almost disbelief in what she was experiencing and telling them. **A precarious alliance** **Anger directed at father:** mother resented the fact that her daughter chose to interact with her partner and not with her. She became very angry with her partner as she felt that there was a collusion with their daughter which exacerbated the mother's difficulties. **Partner not on board:** felt patronised by her partner who would not listen to her concerns which resulted in her feeling very isolated.	Spouse **92nd** percentile	**A precarious alliance** **Difficulties brought them closer:** once her partner started to encourage their daughter to interact with Jill rather than just with himself this resulted in them having a closer relationship**.** **A state of transformation** **Understanding the autism:** EarlyBird course helped Jill to understand that Alison's behaviours were not deliberate. **Getting down to their level:** Jill felt that the PECS gave her the ability to get down to Alison's level in terms of approaching communication in a way that was understandable to Alison. She realised that if she did not change her own communication and interaction behaviours then Alison's communication would not improve. **Interaction and communication:** Jill felt that the PECS gave Alison a way of connecting with her which resulted in Jill feeling closer to Alison. **A journey well-travelled** **Responsibility and support:** once the assessment started Jill felt she could hand responsibility over to the professionals who would shoulder some of the burden. Jill explained that before the assessment she had felt very alone, but once the professionals became involved and offered support and a process of assessment she felt as though she was being led out of the wilderness.	Spouse **65th** percentile	**Quality and amount of visual contact and ability to get down to child's level = 4** **Quality and appropriacy of language used by mother = 4** **Quality and amount of gestures and non-verbal clues used to support understanding = 3** **Mother demonstrates flexibility and creativity to engage her child = 3** **Total score = 14** Mum appeared quite confident with interaction with child. Used excellent strategies such as exaggerated tone of voice, anticipation and forced alternatives to maintain her attention. Child attempted to control situation at times but mum was able to keep control in a subtle way, although this did cause the mother some anxiety. Mum still requiring confirmation that child loved her by asking for a kiss, possibly still holding onto the fear of rejection.

			Process: Jill felt that the clear process in terms of knowing exactly what would happen as they went through the diagnostic assessment helped her to come to terms with the diagnosis as she was involved along the way.		
Sally & Duncan (2)	**The challenge of others** **Facing other parents:** she would keep herself isolated from others in order that she did not have to face them and answer their questions. **Resentment & jealousy of others:** resented her friends who were able to do things as a family and she was unable to do any of those activities. **Others' lack of understanding:** whilst some family and friends tried to understand her difficulties she felt that others made no attempt to understand the day-to-day challenges she faced.	Spouse **100**th percentile	**A state of transformation** **Understanding the autism:** EarlyBird helped Sally to understand the triad of impairments and how the brains of children with autism differed to those with no autism. **Acceptance & the future:** the EarlyBird course allowed Sally to face the diagnosis in a supportive environment, and with the increased understanding of the autism and an acceptance of the diagnosis Sally was able to think about the future for the first time without feeling a sense of dread. This acceptance and support enabled her to see Duncan for the first time for who he was rather than an autistic child. **A journey well-travelled** **Process:** for Sally the goals that they were set, the support she was given and the time the assessment took were all important factors which helped her accept the diagnosis and feel part of it.	Spouse **4**th percentile	**Quality and amount of visual contact and getting down to child's level = 5** **Quality and appropriacy of language used by mother = 5** **Quality and amount of gestures and non-verbal clues used to support understanding = 4** **Mother demonstrates flexibility and creativity to engage her child = 4** **Total score = 18** During the session he was very keen to watch the television but she managed to maintain his attention through interactive play, and to avoid having to switch the TV on. She set boundaries for him by telling him that first he had to do something of her choosing and then he could have the television on.
Delia & Jake (3)	**A precarious alliance** **Partner not on board:** partner refused to discuss concerns with her; therefore, she became heavily reliant on her mother for support.	Spouse **85**th percentile	**A precarious alliance** **Help with communication:** the information that Delia gained on the EarlyBird course enabled her to explain the autism to her partner, which promoted communication between the couple. **A state of transformation** **Understanding the autism:** the EarlyBird	Spouse **70**th percenti**le**	**Quality and amount of visual contact and getting down to child's level = 4** **Quality and appropriacy of language used by mother = 3** **Quality and amount of gestures and**

			course equipped her with the understanding of how Jake thought about things and gave her the knowledge of how to interact with him. **Getting down to their level:** Delia was given the information through EarlyBird and PECS about pitching her communication at the same level as her child, which she felt made a tremendous difference to Jake. **Interaction and communication:** although Delia did not like the idea of Jake using an augmentative communication system she did embrace the fact that it promoted interaction with her.		**non-verbal clues used to support understanding = 4** **Mother demonstrates flexibility and creativity to engage her child = 3** **Total score = 14** Mother appeared to be animated once she settled into the session. She used a warm facial expression and appeared to be very relaxed and confident. She was competent in her use of communication strategies to meet his needs. For example, using repetitive language, following his lead, giving choices, matching her language to his level of understanding and using gestures.
Sheila & Jack (4)	**A precarious alliance** **Partner not on board:** mother felt that her partner was unsupportive as he refused to discuss the difficulties and this resulted in her feeling that he did not care for her.	Spouse **50th** percentile	**A precarious alliance** **Help with communication:** the EarlyBird course gave this couple a shared understanding of Jack's difficulties, which facilitated communication between them. **A state of transformation** **Understanding the autism:** Sheila felt that the understanding she gained from the EarlyBird course enabled her to accept her child for who he was rather than having unrealistic expectations of him, which lifted the burden of guilt that she felt. **Getting down to their level:** Sheila realised that reducing her language to match that of Jack's level of understanding helped him tremendously to communicate with her. **Interaction and communication:** The increased interaction which was initiated by using the PECS resulted in Sheila feeling less of a failure as a mother.	Spouse **35th** percentile	**Quality and amount of visual contact and getting down to child's level = 3** **Quality and appropriacy of language used by mother = 3** **Quality and amount of gestures and non-verbal clues used to support understanding = 3** **Mother demonstrates flexibility and creativity to engage her child = 2** **Total score = 11** Mother unaware of how much she took the lead during interactions and communications.

			Acceptance and the future: With the increased understanding through EarlyBird and improved interactions with the PECS, Sheila felt that there was hope for improvements in the future and she was therefore able to see him for who he was without the autism. **A journey well-travelled** **Responsibility and support:** Sheila felt a weight was lifted from her shoulders when she was able to discuss her fears with professionals and was able to talk frankly about issues she felt had previously been taboo. **Process:** because Sheila felt that she had been involved in every aspect of the assessment it was easier for her to accept the diagnosis.		
Jane & Tom (5)	**The challenge of others** **Facing other parents:** felt that others thought she was a bad parent because of her child's behaviours and therefore started to avoid other parents.	Spouse **10th** percentile	**A precarious alliance** **Difficulties brought them closer:** the concerns that they both shared about their son encouraged them to talk to each other and this resulted in their becoming closer as a couple. **A state of transformation** **Understanding the autism:** Jane felt that it was her improvement in understanding the aetiology of autism and the triad of impairments that made the biggest difference to her understanding her child. The use of PECS to request objects also helped her to understand him as she now had a way of knowing what he wanted. **Getting down to their level:** by copying the way that professionals communicated and interacted with Tom, Jane realised that if she changed her behaviour her child's behaviour would also change. **Interaction and communication:** the increase in Tom's interaction with Jane helped her to understand what he wanted which made her feel better about herself as a mother. She felt that his improved communication and interaction gave him confidence as well as her and this	Spouse **25th** percentile	**Quality and amount of visual contact and getting down to child's level = 3** **Quality and appropriacy of language used by mother = 2** **Quality and amount of gestures and non-verbal clues used to support understanding = 4** **Mother demonstrates flexibility and creativity to engage her child = 3** **Total score = 12** Initially the child had his back to the mother which she did not try to rectify. Face to face was only regained when child moved himself. A lot of directing him rather than following his lead. Mother did use quite a lot of gestures

			brought them closer. **A journey well-travelled** **Responsibility and support:** Jane felt supported through the assessment which helped her come to terms with the diagnosis. **Process:** Jane felt that the process was necessary as once the diagnosis was given she had a better understanding of why it had been given because she had been part of the assessments.		to support her communication e.g. pointing, patting knees, hand over hand, shaking head. Very little commenting. Mainly questions or directions. Used some long phrases whereas other phrases were one word phrases. Not always following child's lead. Using language rather than physical prompt to get his attention e.g. 'come back'. Only used repetition once.
Gail & Emily (6)	**A journey well-travelled** **Support for mother as well as child:** Gail felt very sad that she had been offered no support during the time of the assessment or diagnosis and felt lost in terms of what to do with the diagnosis. **Process aided acceptance:** Gail did not feel that the process she had been through helped her in any way, and in fact she felt bitter and frustrated that she had not been listened to and that it had been difficult as she did not feel part of the assessment.	Spouse **92nd** percentile	**A state of transformation** **Relief and empowerment:** Gail felt that the diagnosis empowered her to help her daughter.	Spouse **95th** percentile	**Quality and amount of visual contact and getting down to child's level = 3** **Quality and appropriacy of language used by mother = 4** **Quality and amount of gestures and non-verbal clues used to support understanding = 4** **Mother demonstrates flexibility and creativity to engage her child = 3** **Total score = 14** Appeared to be very confident when interacting with her daughter. She allowed her daughter to lead the game but did take control back again when her daughter appeared to be trying to take control.

13.1 The challenge of others

This theme relates to the relationships that the mother had with other people including family, friends and professionals, and how these relationships affected the relationship she experienced with her child.

13.1.1 Facing other parents

Mixing and interacting with other mothers who had a child of a similar age was a challenge to three mothers. The issue, previously discussed, of being judged as a bad mother resulted in one mother isolating herself from her friends and refusing to attend social occasions because she found it so upsetting:

> *'The child whose birthday it was would not get any attention, all the attention would be on Duncan. I would get upset, he would get upset and the whole thing would be a big drama. So I would just tell people no I can't do that because this is what happens and when I was on my own I would be just really really upset'* (Sally, NVivo line number 328)

Another mother resorted to lying to her colleagues and friends about her daughter's abilities, and pretended she had no difficulties and that she had skills that were beyond her chronological age:

> *'I kept a lot of it to myself, I didn't discuss it with anyone outside of the family and that was a huge strain in work, especially in work, everybody's talking about their children and at one point I was making things up you know, I thought just to shut them up really, and say she's doing this and she's doing that and she's fine you know she's great'* (Jill, NVivo line number 278)

13.1.2 Resentment and jealousy of others

Three mothers expressed feeling jealous of other mothers who had 'normal' children, which appears to have been for two different reasons. Two mothers were jealous of the relationship that other mothers had with their children and saw it as a reflection on their own failure:

> *'Jealous, I was very very jealous of other mothers, I felt like I'd failed, you know all my friends had children, nobody seemed to have anything wrong with their children'* (Jill, NVivo line number 1034)

Another mother resented the fact that other families were able to go out together and enjoy social activities in the community but she was unable to experience this:

> *'Oh my God, none of them knew, they had no idea how hard it was. And I resented them, my friends with other children and I still can't sit in a beer garden on a Sunday afternoon and take my kids… just the stupid things that everyone else does. I can't do it and I feel very sorry for myself'* (Sally, NVivo line number 614)

13.1.3 Lack of understanding

Not being believed and a lack of understanding with regard to the difficulties they were experiencing with their children were expressed by two mothers. This lack of understanding was conveyed not only by family members but also by some professionals, and appears to have reinforced the mothers' feelings of failure:

> *'I was patronised, 'she's only young give her time, she will be all right' and then I got back home and it seemed like I was getting it everywhere. You know I thought it was me, it's me I'm imagining all of this'* (Jill, NVivo line number 258)

13.2 A precarious alliance

The theme a precarious alliance relates to the relationship the mother had with her partner.

13.2.1 Anger directed at father

For one mother anger towards her partner was a particularly strong emotion, and appears to have been related to her perception that her daughter's disability was the fault of one or other of them. As there were no other people in her family with a disability, she reasoned that it must be the fault of her partner. The fact that the child of this couple preferred to interact with the father rather than with the mother, which she felt the father encouraged initially, resulted in her feeling very angry with her partner for encouraging their daughter to behave in this way:

> *'I felt very angry towards him. I never said one word to him but I thought it's got to be his fault'* (Jill, NVivo line number 1012)

13.2.2 Partner not on board

The perception of coping alone with the burden of arranging appointments and worrying about their children's development appears to have been the experience of three mothers. It seems to have been difficult to discuss their anxieties with their partners for fear of having these concerns rejected, as their partners refused to acknowledge the difficulties, despite their children presenting with considerable problems with interaction and communication. This burden was reflected in the scores from the **spouse** domain of the *early emotions* PSI (figure 13.2) in which all but two of the mothers had higher scores than they did in the *later emotions* PSI. Interestingly, two mothers had higher

scores subsequently, one of whom described the fact that having a child with difficulties had brought them closer together as a couple. However, as their awareness of the implications of their children's difficulties increased, this often put a greater burden on the relationship. The second mother who scored high on both occasions had separated from her partner during the time of assessment and diagnosis. All of these mothers felt that this lack of support from their partners put them under considerable pressure:

> *'Going to appointments you know, it was a strain because I kept it all from him'* (Jill, NVivo line number 924)

Delia resorted to relying on support from her mother because she did not receive the support she felt she needed from her partner:

> *'My partner is not really the one who likes to get involved with things. He is just quite happy for me to do the parenting role. I mean, we did talk about things, but…. I have had a lot of support from my mum, I've had a lot of support from my mum. I basically relied on her'* (Delia, NVivo line number 552)

The fear of open discussions between the couples appears to have been rooted in the idea that such discussion would give way to acknowledgement of the difficulties. Therefore for one couple it was easier not to discuss these issues:

> *'But in our relationship it was just a little bit….we didn't speak, we talked about it but it was like okay it was happening and there is not much we can do. Besides that there was just the nonspeaking really side of things'* (Sheila NVivo line number 489)

13.2.3 Difficulties brought them closer

Two mothers felt that once they had attended the EarlyBird sessions they and their partners began to understand the difficulties that their children were experiencing. This shared understanding appears to have strengthened their relationship:

'I think maybe it's brought us that little bit more together because we've got that little bit of understanding you know because he belongs to us because our little boy has brought us that little bit closer to each other' (Jane, NVivo line number 177)

For another couple the father started to encourage his daughter to interact with the mother rather than with him, which resulted in the mother feeling less angry with her partner, reinforced their relationship and brought them closer together:

'She would come to me, and that was encouraged by him, very much encouraged by him' (Jill, NVivo line number 420)

13.2.4 Help with communication

For two mothers the EarlyBird course appears to have given them the confidence to discuss their children with their partners in relation to the difficulties experienced due to the autism. Neither of these mothers felt able to do this prior to gaining the knowledge during this course. For Delia it gave her the confidence to support her son when she felt that her partner was lacking in understanding regarding his disability:

'Sometimes you have to keep reminding him because there are some things that I do and he says you shouldn't do that because he's not going to learn, and I'll say to him, you've got to realise he has autism, so you can't do things like you would with a normal child' (Delia, NVivo line number 574)

For Sheila this understanding was shared with her partner and gave them both the strength to examine and manage behaviours by supporting each other, an issue which had previously been very difficult:

'I mean sometimes Jack's doing something that he shouldn't, misbehaving and you have to think what is the reason behind this. You know there's got to be something, and you shout and then you'll have to remember back to look at why he is behaving in that way and it's only then that one of us will go, come on, hang on a minute it might not be that, let's see what it is together' (Sheila, NVivo line number 500)

13.3 A state of transformation

This theme relates to the mother's perceptions of the impact of the interventions that the mother and child received.

13.3.1 Understanding the autism

The concept of understanding the autism was tremendously important to five of the mothers, and there appears to have been several different reasons for this importance.

All of these mothers felt that they were empowered by their increase in knowledge and understanding as to why their children behaved in particular ways. This appeared to give the mothers the ability to allow themselves to relinquish responsibility for their children's behaviour. As previously discussed, prior to this knowledge, several mothers had felt that they were responsible for their children's lack of or difficulties with communication and interaction with themselves, or had even blamed their children for purposely choosing not to communicate or interact with them. The knowledge gained through the training helped them to alleviate these concerns:

> *'It really did help me to understand her. I didn't feel I ever understood her, you know really until the EarlyBird course. You know, I needed to understand why she was like that, why she would do these things. Once you start to understand that she is not doing it deliberately, she can't help it, it's great'* (Jill, NVivo line number 1024)

The ability to now understand what their children were thinking almost became a revelation to some of these mothers. The knowledge of how children with autism experience the world and the difficulties they have in the triad of impairments not only allowed the mothers to appreciate what their children may

be experiencing, but also provided confidence and knowledge of how to help their children:

> *'That was a lovely feeling for me to think I might be able to understand him, because I didn't understand anything before that, but now I've got a means of possibly contemplating what is just going on in his head. And that was a big deal'* (Sally, NVivo line number 608)

In turn, this increased understanding appeared to strengthen the bond between the mother and her child:

> *'I think our relationship is a lot better because I think I understand him more now'* (Delia, NVivo line number 709)

> *'God the EarlyBird was really good because it taught you a lot of things that you wouldn't think about. It taught you how to get through to your child and how to do certain things with your child. It especially taught me how to understand him which I think was the main thing'* (Jane, NVivo line number 508)

Although all of the mothers felt that the majority of their understanding had been gained from the EarlyBird course, they also discussed gaining knowledge from working with and observing the professionals involved with their children. Several mothers appear to have emulated the interaction and communication used by either the speech and language therapist or the Portage worker.

Interestingly, the mother from the unusual case did not discuss understanding her daughter or the autism. However, she had not been offered nor had she accessed any autism-specific training for herself or her daughter, and therefore may have been unaware of the benefits that an increased understanding may have had for the mother-child relationship.

13.3.2 Getting down to their level

Increased understanding appeared to be associated with the mother's ability to 'get down' to the child's level. Again, the majority of mothers appeared to have developed these skills via the EarlyBird course, or by observing professionals interacting and communicating with their children. Mothers subsequently attempted to match their language to their children's level of understanding, to be face-to-face with their children, and to be flexible and creative in their attempts to engage their children, rather than insisting on the children's engagement in activities chosen by them. Although these strategies are related to an increased understanding of the autism, as they involve specific activities that they could imitate and practise, they subsequently increased the mothers' confidence to communicate and interact with their children:

> *'it was the way that I communicated with him, it was my language to him, because you can't just have a normal conversation with a child with autism. You have to change the way like want to tell him something'* (Delia, NVivo line number 313)

> *'I had to strip it right back and just use one or two words. And at the time he was reacting to it and it actually helped me you know'* (Sheila, NVivo line number 475)

> *'you do have to get down on their level to be able to express yourself, because if you don't they just get frustrated and angry and you just get frustrated and angry. So basically I've learned how to communicate as best I can and the most important thing is that I can understand him now'* (Jane, NVivo line number 551)

The ability of the mothers to be flexible with their communication and interaction skills, and to match these skills to the needs of their children was observed during the mother-child interaction. Scores which reflected the quality of these interactions and communications ranged from 11 to 18 out of a possible 20 (see figure 13.4 for individual scores), the lower scores demonstrating continued difficulties with using these skills.

13.3.3 Communication and interaction

The concepts of communication and interaction were used interchangeably, with three mothers explicitly describing their elation when their child chose to interact with them. Although the Picture Exchange Communication System was used initially as an augmentative communication system, it also enabled the child to initiate an interaction with their mother. It appears to have been the initiation of this interaction by the child that provided the mother with the most hope. Jill described it as a 'wonderment' because she finally felt she had her daughter:

> *'It was just a wonderment. It really was. It was like, like I had my daughter I had her you know, because before she just didn't communicate with me. She didn't, and to me, that was the first time when she started bringing me those sentence strips'* (Jill, NVivo line number 457)

When one mother was asked what it was that had made the biggest difference to her when using the PECS, she stated that it forced her child to interact with her but it also made her think that her child had previously purposefully chosen not to interact with her:

> *'Well, because he had to interact with me now'* (Delia, NVivo line number 523)

It appears, however, that it was not only the fact that the child was interacting with the mother, but also the fact that the child was initiating the interaction that was so important to the mother:

> *'I think it was just the interaction. It was the interaction between us and the fact that he was actually coming up and asking me for things'* (Sheila, NVivo line number 438)

13.3.4 Acceptance and the future

The increased knowledge and understanding that these mothers gained from the EarlyBird course and from observing other professionals appears to have given Sally and Sheila confidence to accept their children's diagnosis, and whatever the future held for them and their children. With this acceptance also came the ability to see their children for who they were rather than children with autism:

> *'I think it was the fact that we saw Jack for the first time, it sounds terrible doesn't it. I saw him for the first time'* (Sheila, NVivo line number 242)

Although Sally and Sheila had obviously come to terms with the diagnosis, not all mothers felt the same way as some still found aspects of their children's disability difficult to come to terms with.

13.4 A journey well-travelled

This theme encompasses the process of assessment and diagnosis.

13.4.1 Responsibility and support

The process of the assessment, and the interaction with the professionals involved in the assessment and those who delivered the interventions, allowed two of the mothers to almost hand over the responsibility or burden to the professionals. For one mother it was the actual process of assessment from the outset that gave her the support:

> *'I think that once we started on that pathway. I felt, like almost as if arms had embraced me and they were there to help me'* (Jill, NVivo line number 340)

Although this mother felt supported by the majority of professionals, she also felt patronised by others which reinforced her self-doubt:

> *'she was getting distressed and he was patronising. Don't worry, he said, don't worry, she's not getting distressed she is normal'* (Jill, NVivo line number 852)

For another mother it was the acknowledgement by the professionals that her child was presenting with behaviours which the professionals had seen in other children which confirmed to her that she was not imagining her child's difficulties:

> *'it was literally when we met the professionals, the things they were saying like that Jack was not doing at the time you know the typical behaviour like lying on the carpet, the things he was doing they just made it sound like we were not the only ones… that was more helpful than anything, it was just like a big release, it was like a big weight had been lifted off my shoulders'* (Sheila, NVivo line number 367)

The support that the mothers received from the professionals appears to have been important to three of them because it was specifically aimed at them and not focused upon the needs of their children:

> *'I knew that there is a support network, a support network there for me as well, and it was that support I hadn't had. I just felt well relief and I felt relieved that I was in the right place'* (Jill, NVivo line number 351)

13.4.2 Process aided acceptance

The process, which included the time the assessment took, the interventions, strategies, goals, and the support that these mothers were given, appeared to have helped them to come to terms with and understand the diagnosis. Several mothers stated that because the assessment lasted for a considerable number of weeks, this helped them to move from a position of denial and lack of

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understanding to gradual acceptance. Several mothers felt that if the assessment had taken place over only a couple of weeks this would not have given them the opportunity to come to terms with the diagnosis. Equally important to these mothers was the fact that they were given goals to achieve during the assessment period, which appears to have given them a sense of purpose:

> *'I just think that the whole thing's been fantastic and even although I was worried about all these appointments I realise that they are all essential and are not as daunting as one thinks. It helps you to understand in the long run why'* (Jane, NVivo line number 454)

> *'It was the fact that it was a long time and we had time to adjust to it as well, because that was really important'* (Sheila, NVivo line number 602)

However, not all mothers felt that the process of assessment and interventions was always easy. Two mothers talked about how they felt that the professionals were an intrusion in their life, and they resented the fact that other mothers did not have people telling them how to bring up their children:

> *'At first I didn't like the intrusion, I didn't like the intrusion cos I felt almost strained. Just like being sectioned out. Other mothers can just get on with their lives, they can just do what they want with their children and never have any of these people coming into their house'* (Jill, NVivo line number 919)

For the mother of the unusual case, unlike the other mothers, it had taken her a considerable length of time to persuade professionals that her daughter was experiencing difficulties. Because of this she felt very let down and disappointed that it had taken so long. Whilst the majority of other mothers felt they had been supported throughout the process, enabling them to feel stronger and more accepting of the diagnosis, this mother, although relieved by the diagnosis, felt unsupported and as though she had been through a 'marathon':

Q. So are you saying you were relieved by the diagnosis?

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A. 'Yes I was, I remember saying to Dr......... as I left thank you very much you don't realise what a difference this is going to make' (Gail, NVivo line number 796)

'I think when I first got the diagnosis I felt disappointed that I had been through all of that. For myself I felt kind of like I had been through a marathon' (Gail, NVivo line number 547)

Figure (13.2) Spouse scores from the PSI

Spouse
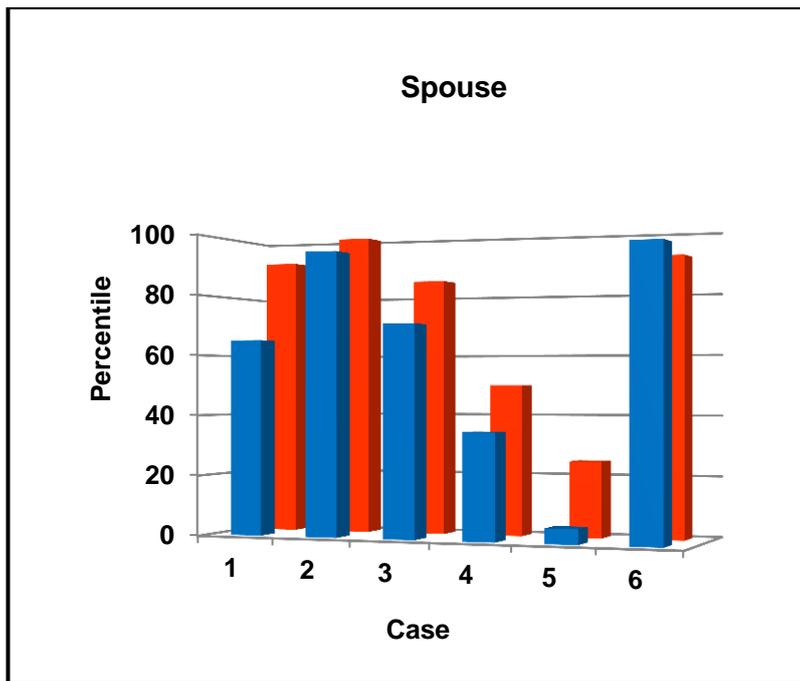
Figure (13.3) Maternal behaviour scores from the mother-child interaction

Maternal behaviours
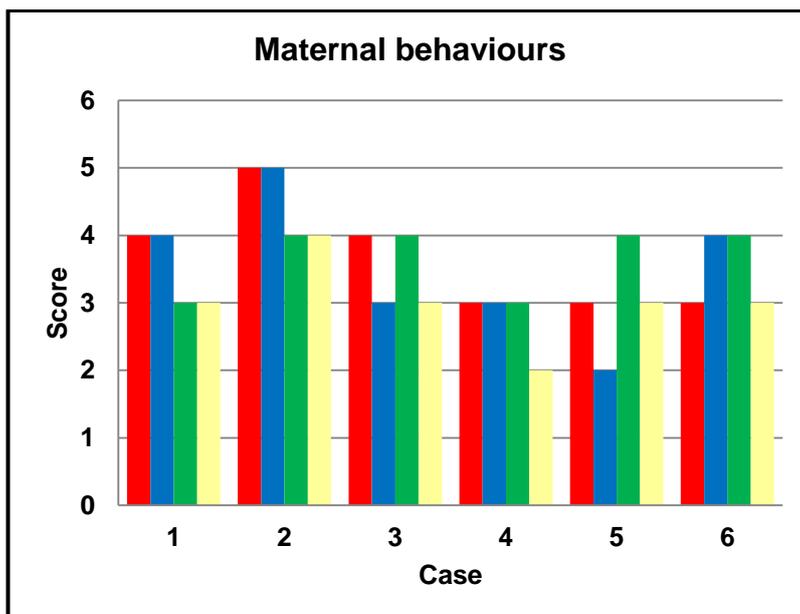
Legend

<table>
<tr><td style="background:red;">   </td><td>Quality and amount of visual contact and ability to get down to child's level</td></tr>
<tr><td style="background:blue;">   </td><td>Quality and appropriacy of language used by mother</td></tr>
<tr><td style="background:green;">   </td><td>Quality and amount of gestures and non-verbal clues used to support understanding</td></tr>
<tr><td style="background:lightyellow;">   </td><td>Mother demonstrates flexibility and creativity to engage her child</td></tr>
</table>

Figure (13.4) Maternal total behaviour scores from the mother-child interaction
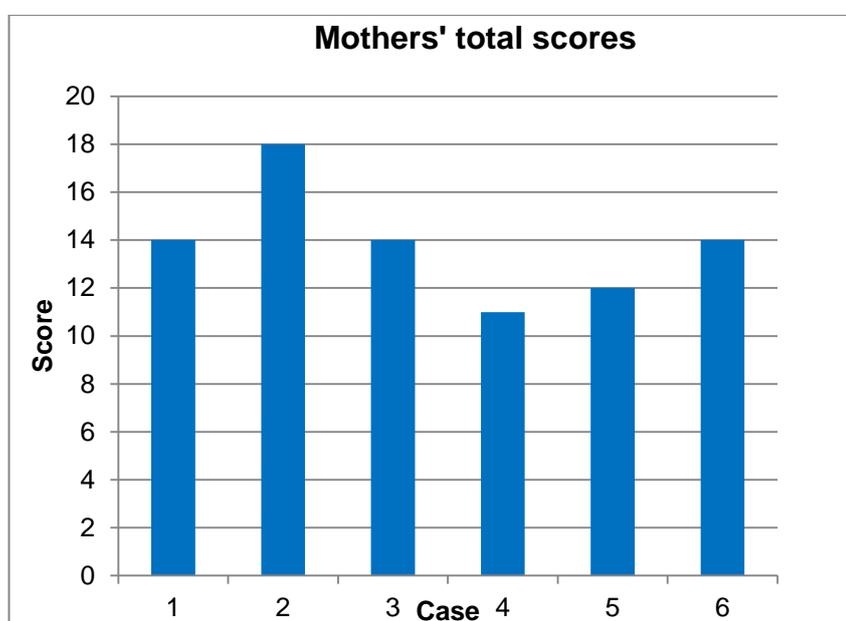
13.5 Key results from facilitators and barriers

➤ Mixing and interacting with other mothers who had children of a similar age was a challenge and resulted in resentment and jealousy.

➤ Lack of understanding by family members and some professionals reinforced the mothers' feelings of failure.

- ➢ Mothers felt resentment towards their partners as they had to carry all of the burden.

- ➢ Two mothers felt that the shared understanding once they had attended the autism training strengthened their relationship with their partners.

- ➢ Mothers felt empowered by their increase in knowledge and understanding as to why their children behaved in particular ways.

- ➢ An increased understanding of their children and the autism enabled mothers to get down to their children's level.

- ➢ Mothers were elated when their children chose to interact with them.

- ➢ The process of assessment aided their acceptance of their children's diagnosis.

13.6 Conclusion

This dimension encompassed the five themes **the challenge of others, a precarious alliance, a state of transformation and a journey well-travelled.**

The following chapter presents the discussion and conclusions of this study and pulls together the results from the previous four chapters. Recommendations for clinical practice are also offered.

CHAPTER FOURTEEN

CONTRIBUTION TO KNOWLEDGE

The previous four chapters presented the results from phase two of the analysis and offered insights into the difficulties mothers experience in their relationship with their children.

14.1 Introduction

This chapter offers a discussion in relation to the results and conclusions of this study and insights into how the findings contribute to the wider knowledge base. This robust exploratory and descriptive study aimed to provide an understanding of mothers' relationships with their autistic children using case study methodology which employed mixed methods data collection. This aim has been achieved and one of the key emergent findings from this study was that mothers reported feeling rejected and unloved by their children as a direct consequence of their children's communication and interaction difficulties.

The literature review revealed a paucity of studies which specifically focused on this phenomenon, and therefore this study has gone some way to addressing this knowledge gap. The difficulties that these mothers experienced in forming and maintaining a positive relationship with their children have been emphasised through this study, and furthermore the application of Hinde's (1995) relationship model has offered a unique framework and perspective from which to explore this relationship compared to the traditional attachment theory model (Ainsworth et al., 1978; Bowlby, 1980).

The use of Hinde's (1979) model, which was based upon his theoretical perspective of relationships, enabled the conceptualisation of the dyadic relationship using various dimensions which facilitated the exploration and analysis of this relationship (chapter 9.3, p. 216). The use of this model emphasised the importance of the diverse influences of internal and external dynamics upon the relationship, providing a more holistic view of this relationship and therefore enabling unique contributions to the knowledge of this phenomenon.

The rationale for this study was to increase the understanding and knowledge of this dyadic relationship, and not to carry out any specific evaluation of the effects of the autism strategies. However, this study did highlight certain insights into the effects of early interventions. The findings from this study could therefore be used to inform the understanding of professionals and policymakers involved with these families, in order to more successfully promote the establishment of a robust relationship in these dyads.

This chapter synthesises the results from chapters ten to thirteen and discusses three overall findings which are contextualised by the wider literature, namely:

- Feeling rejected and unloved

- Failure as a mother

- The effects of responsiveness and synchrony

Prior to this a discussion regarding the contribution of Hinde's theoretical framework will be provided. This will be concluded by a discussion of the overall findings.

14.2 Hinde's diverse theoretical framework

The exploration of the relationship between the mother and her child has traditionally been viewed from the perspective of attachment theory (Ainsworth et al., 1978; Bowlby, 1980) with several studies including children with autism (Sigman & Ungerer, 1984; Rogers & Ozonoff, 1993; Capps, Sigman & Mundy, 1994; Dissanayake & Crossley, 1996; George & Solomon, 1999; Rutgers et al., 2004; Prior & Glaser, 2006; Rutgers et al., 2007a; van IJzendoorn, Rutgers, Bakermans-Kranenburg, Swinkels, van Daalen, Dietz, Naber, Buitelaar & van Engeland, 2007). However, the findings from this study have demonstrated that viewing the relationship from this perspective does not enable a holistic interpretation of the complexity of the relationship, nor does it take into account the various factors which influence this relationship.

Hinde (1979) suggests that a relationship is built upon interactions that have happened in the past and reflects the perceptions and anticipations of the future interactions. The findings from this study suggest that these mothers were highly influenced by the previous behaviours of their children, which had an effect upon their perceptions of their children's love for them as well their subsequent interactions with their children. Hinde also suggests that the responses of one partner within the dyad are highly influenced by the other and that the quality of the interaction is as vital, if not more so, as the actual interaction itself. The mothers in this study often reported feelings of failure due to the negative responses or interactions from their children and perceived that they were failing mothers (see section 14.4). Consequently, these negative self-perceptions also had an effect upon their subsequent interactions with their children.

Hinde proposed that the parent-infant relationship be explored using seven categories which structured the observations during the interactions. These categories were consistent with the observational categories already developed for this study based upon previous work (Lemanek et al., 1993; Doussard-Roosevelt et al., 2003; Horowitz et al., 2005). Hinde also proposed five dimensions which enabled the exploration and analysis of the relationship and the integration of the findings from all sources of data into clear categories. These dimensions were re-named for the purpose of this study but retained the original representations. They facilitated the cross-case analysis of all of the data and aided the description and narrative associated with each component of this complex relationship.

Exploration of the literature did not reveal any previous studies where this theoretical framework had been used to explore mothers' relationships with their children with autism. The use of this framework enabled the synthesis of the complex data generated in this study and provided unique insights into the exploration of this relationship. It is therefore proposed that this diverse theoretical framework be utilised in future studies and should be used, not only with the mothers, but also to understand fathers' relationships with their children.

14.3 Feeling rejected and unloved

The initial key finding from this study was the fact that mothers did not feel loved by their children due to their children's inability to demonstrate love. The findings indicated that all of the mothers, except Gail (the unusual case),

experienced difficulties in forming and maintaining a connection or an attachment with their children, as a result of their children not initiating an interaction or communicating with them. This is consistent with findings from other studies (Hoppes & Harris, 1990; Sakaguchi & Beppu, 2007). This difficulty forming an attachment resulted from the mothers deeming the interactions within the relationship to be very one-sided and their having to make all of the effort to interact and communicate with their children. These findings are supported within other studies (Mundy et al., 1994; Mundy & Sigman, 2006; Davis & Carter, 2008; Beurkens, Hobson & Hobson, 2012). Furthermore the specific difficulties with children's social relatedness were found to be associated with relationship problems in a study conducted by Davis & Carter (2008). The sense of rejection that the mothers in this study experienced, also corroborates the findings of Howe (2006).

The literature base, which was reviewed in chapter four and five, did not reveal any previous studies which specifically explored mothers' perceptions of being unloved and rejected because their children did not communicate or interact with them. These mothers' inability to understand that their children were unable to display these intimate behaviours, and to adapt their own behaviour in accordance is in contrast to the findings of Koren-Karie, Oppenheim, Dolev & Yirmiya (2009), with these authors suggesting that mothers were able to adapt their behaviours despite their children's significant difficulties with attachment.

14.4 Failure as a mother

For some mothers this sense of rejection and perception that their children did not love them resulted in their not reciprocating love for their children, leading to feelings of guilt and failure.

Because the children in this study were unable to communicate, several of these mothers were unable to understand their children's needs, which for some resulted in an exacerbation of this sense of failure because they felt that mothers should know instinctively what their children need. These findings are supported by the study conducted by Nealy, O'Hare, Powers & Swick (2012).

All of the mothers shared characteristics in relation to their negative emotions which were directly attributed to their children's difficulties, and all experienced some type of negative emotion at one time or another. These emotions had a considerable impact upon their lives and pervaded the early years of their children's lives. These findings are similar to results from other studies (Altiere & Von Kluge, 2009; Hayes & Watson, 2012). However, this present study revealed that for some mothers this was exacerbated by observing the communication and interaction of typically developing children with their mothers and resulted in them craving for their children to be the same as other children.

14.5 The effects of responsiveness and synchrony

The concepts of responsiveness and synchrony, competence and confidence are intertwined and interdependent. It appears that these mothers' lack of responsiveness and synchrony affected their confidence, which resulted in a further lack of competence and vice versa. Equally, an increase in or better understanding of responsivity and synchrony had a positive effect on the mothers' competence and therefore confidence. All of the mothers in this study, except one, experienced considerable difficulties with what they perceived was their responsiveness, consistent with the findings from other studies (Rodrigue et al., 1990; Yoder & Warren, 1998; Tomanik et al., 2004; Hassall, Rose & McDonald, 2005). This lack of responsiveness or competence was considerable prior to mothers receiving training. However, following the training mothers reported an improved understanding of their children's difficulties and it provided them with autism-specific communication strategies. Similar to the study by Keen, Couzens, Muspratt & Rodgers (2010), the findings of this study demonstrated that early parent intervention, which focused upon improving understanding of the core difficulties related to autism and improving parents' interaction and communication with their children, resulted in increased parental self-efficacy. This concept of self-efficacy is described by Bandura (1977) as the measure of one's own competence to complete tasks and reach goals. For three of the mothers the difficulties they experienced with communication and interaction were exacerbated by their perception of being judged or disbelieved by others, resulting in a further deterioration in their lack of confidence. For some mothers this resulted in their isolating themselves or fabricating their children's abilities which reinforced their feelings of failure. These findings are supported by a study conducted by Nealy et al. (2012), who found that having a

child with autism had a negative social impact and that other family members, including a spouse, did not understand the experiences of these mothers.

The introduction of PECS enabled these children to initiate an interaction with their mothers which is in line with earlier studies (Howlin et al., 2007; Lerna, Esposito, Conson, Russo & Massagli, 2012). This increase resulted in the mothers perceiving that their children had intentionally chosen to interact and communicate with them rather than use them as a tool to obtain objects. Several mothers felt that their ability to communicate and interact with their children also improved following attendance on the NAS EarlyBird course, where they were taught strategies to augment their own, as well as their children's, interaction and communication skills. This gain in knowledge, competence and confidence is consistent with previous studies into the effects of parent training for parents of pre-school children with autism (Anderson et al., 2006; McConachie & Diggle, 2007).

Although all of the mothers and children, except Gail (the unusual case), had received training in communication and interaction strategies, which did result in an improvement in these skills, all of the children did continue to have difficulties with their communication and interaction (observed during the mother-child interaction; figure 7.2, p.130). The mothers were able to recognise their children's continuing difficulties and reflected these thoughts and observations in their reporting in the later emotions PSI (**Reinforces Parent domain**). Because the children's interaction and communication had improved compared to what it had been initially, there was a discrepancy between how the mothers described their relationship with their children and how they actually interacted with their children, which is consistent with the findings of Hinde (1979).

Five mothers, including Gail (the unusual case), appeared confident in their interactions with their children; however, Jane (case study 5), who scored higher in her competence score on the *later emotions* PSI than she had on the *earlier emotions*, appeared anxious during her interaction with her child. She struggled to implement the strategies that she had been taught, but it is possible that once Jane's knowledge and understanding grew so did her self-actualisation, which Maslow (1965) describes as being achieved when all basic and mental needs are fulfilled and the "actualization" of the full personal potential takes place.

The results from the *early emotions* PSI (child mood) reflected the perception the mothers had of their children's affect, and five mothers had extremely high scores (96th-100th percentile), including Gail (the unusual case). Interestingly, five of the *later emotions* scores remained high (85th- 95th percentile). Again, this may be related to mothers' perceptions that their children continued to have significant difficulties with interaction and communication but were reconciled to this and did not necessarily regard it as a reflection of their parenting, demonstrated in the fact that the *later emotions* depression scores were all lower.

The *early emotions* total stress score on the PSI for all six mothers was exceptionally high and ranged between the 96th and 100th percentile, reflecting the strain that they felt during this time. Sally and Jane, who had received treatment for clinical depression, continued to have high scores in the *later emotions* total stress score, whereas the others had scores between the 72nd and the 40th percentile. Gail (unusual case) also continued to have a high total

stress score, again possibly reflecting the fact that she had received no professional support or autism-specific strategies.

The increased knowledge and understanding that these mothers gained, either overtly during specific training or covertly by observing professionals' interaction and communication styles with their children, allowed these mothers to relinquish responsibility by acknowledging that their children's difficulties were not the fault of personal failings. This also gave these mothers confidence to engage with their children using more successful strategies than they had previously used, despite their children's continued difficulties.

The increase in the children's communication and interaction following the implementation of the PECS, and mothers' increased understanding and competence following the EarlyBird course, resulted in increased confidence which further improved the children's communication and interaction even though they continued to demonstrate difficulties in these areas. Subsequently these acts were perceived by the mothers to be a sign of their children's love for them, which in turn altered their feelings towards their children in a much more positive way, and for some meant becoming a *'proper mother'* (Jill). The ability to relinquish responsibility and the successful interactions that ensued therefore appeared to have strengthened the mother's relationship with her child. The dynamics and the influences of this relationship can be seen in figure (14.1)

Figure (14.1) The dynamics and influences of the mother-child relationship
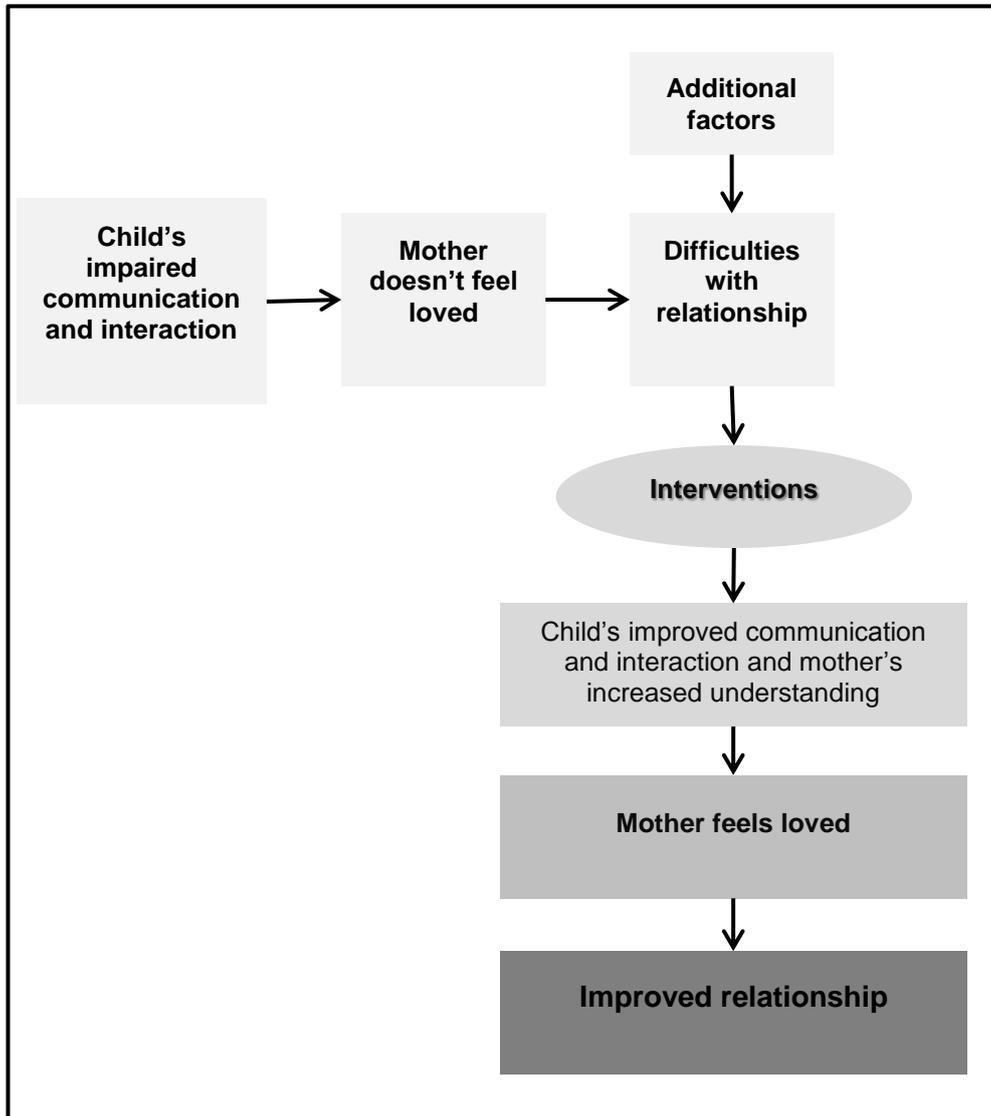
This study produced certain findings which were consistent with previous studies; however, it also produced some unique findings which contribute to a greater understanding of this dyadic relationship which are detailed in table (14.1).

Table (14.1) What this study contributes to knowledge

What this study contributes to knowledge
1. Mothers felt rejected and unloved due to their children's inability to communicate and interact. 2. Mothers felt a failure because they were unable to understand their children and were unable to communicate or interact with their children. 3. The introduction of autism-specific interventions enabled the children to initiate an interaction with their mothers and enabled the mothers to better understand their children, resulting in their feeling loved.

14.6 Conclusion

The challenge of bringing up a child with autism has seen significant research over the past ten years and various studies have proposed a range of parent and child factors contributing to these challenges. A considerable body of research has contributed to the understanding of autistic children's attachment to their mothers (Sigman & Ungerer, 1984; Rogers & Ozonoff, 1993; Capps et al., 1994; Dissanayake & Crossley, 1996; George & Solomon, 1999; Rutgers et al., 2004; Prior & Glaser, 2006; Rutgers et al., 2007a; Van IJzendoorn et al., 2007). However, it is argued that these studies do not encompass a holistic view of the relationship. In this study Hinde's (1979) diverse theoretical framework was adopted as a means of exploring this relationship.

This study has demonstrated that early interventions which focus upon aiding communication and interaction in the child, and increasing the mother's understanding of these core difficulties, can enhance their relationship.

There are no other published studies to date which explore the mother's relationship with her young autistic child who is non-verbal and who has considerable difficulties with social interaction. This study has demonstrated that these core child deficits do have an impact upon the mother's relationship with her child. In addition to these core difficulties, other factors such as the mother's perceptions that she was being judged by others and her observations of typically developing children's interaction and communication also had an impact upon this already precarious relationship.

The following chapter will discuss the limitations to the study.

CHAPTER FIFTEEN

LIMITATIONS OF THE STUDY

The previous chapter offered a discussion in relation to the results and conclusions of the study. This chapter will discuss the limitations of this study.

15.1 Introduction

As with any research there are certain limitations to this study, which result in a threat to the rigour and which threaten the transferability, dependability and credibility and need to be acknowledged and considered when designing any future research studies. These limitations will be discussed and the following chapter will make recommendations for future research. The limitations can be viewed from the perspective of the trustworthiness of the study.

15.2 Trustworthiness

The concept of trustworthiness (Lincoln & Guba, 1985) has already been introduced in chapter (6.7.1, p.107), and strategies which were implemented in order to enhance the trustworthiness of this study included confirmability, transferability, dependability and credibility. It is not possible, however, especially in qualitative research, to meet criteria which will 100% guarantee adherence to the recommended strategies and it has to be acknowledged that bias was unavoidable. Although strategies such as those suggested by Hassan

(2006) (see chapter 6.8.1, p.111) were implemented to reduce the effects of respondent bias and reflexivity was used to reduce this effects of researcher bias (chapter 6.8.5, p.114), there were nevertheless limitations to the transferability and credibility of this study which are discussed below.

15.2.1 Transferability

A possible limitation of this study was the number of case studies involved. The number of cases included in the study was thought to be sufficient to allow for the in-depth exploration of the phenomenon in question, and was also dictated by the considerable data generated from the various different methods of data collection and the time taken to transcribe and analyse this data. The study implemented a complex methodology which involved several different methods of data collection and several layers of analysis, and it was extremely challenging to ensure that the methodology or study design was presented in a clear and well-defined style for the reader. The study did therefore result in a robust exploration and description of the mother's reported and observed relationship with her child. It is not possible to transfer the results from this study to the wider population of mothers with young children with autism; however, it is still possible according to Lincoln & Guba (1985) to transfer the results to a similar group with similar context. Suggestions to mitigate this limitation are discussed in chapter 16.2, p.305.

15.2.2 Credibility

A further limitation was the selection criteria of the participants. All were known by me and the children had been treated by me in the past; therefore, it is possible that the mothers felt indebted to me and therefore agreed to participate, increasing the possible likelihood of respondent bias (King & Bruner, 2000). This influence would not only have had an effect upon the mothers but it also, unwittingly, had an effect upon my interaction with these mothers and my interpretation of the findings. Except for one mother who declined to participate, all of the mothers who were approached were very eager to participate in this study. It is possible therefore that the mothers of children unknown to me may have differed in their responses and may have offered a different perspective. It is also possible, however, by the fact that they were eager to participate, they were more likely to openly and honestly share their experiences compared to mothers who were less eager to participate. There is therefore a strong possibility, despite using strategies such as reflexivity and reflexive bracketing (see chapter 6.8.5, p.114) to avoid this, and attempting to remain impartial, that researcher bias was present.

15.3 Summary

As already discussed any study, whether it be qualitative or quantitative, will include limitations as research is never possible without extraneous factors affecting the results (Jootun et al., 2009). It is essential that as a researcher I acknowledge these limitations and have discussed how these may affect the rigour of this study and the transferability to the wider population of mothers with

young autistic children. Recommendations for further research which would mitigate these limitations are discussed in the following chapter along with proposals as to how these could be implemented.

CHAPTER SIXTEEN

PROPOSALS FOR FUTURE RESEARCH

The previous chapter discussed the limitations of this study and this chapter will discuss proposals for further research.

16.1 Introduction

At the initial outset of this study the aim was to explore the effects of the autism-specific strategies (PECS and EarlyBird) on the mother's relationship with her non-verbal child. However it became apparent early on in the study that this was not possible within the remit of such a small qualitative study and required a much larger scale study. It was imperative to explore the dynamics of the mother-child relationship initially before attempting to examine the effects of any interventions. This study has achieved its aim and has highlighted the challenges that these mothers have in forming and maintaining a relationship with their children. It has also however raised other questions which would benefit from further exploration and investigation, such as further exploration of the dyadic relationship, the effects of the autism-specific strategies upon this relationship, the support required by these mothers to implement the autism specific strategies, and therapists' understanding and expectations of these dyads. A further study could also explore the relationship of fathers with these children. These separate research questions would require different research methodologies as it would be impossible to explore or investigate each question using the same design as this present study. Therefore the following proposals

for further related research and research designs, which will test out the theoretical insights generated from this study, are suggested:

- The impact of children's significant communication difficulties upon mothers

- The impact of PECS and EarlyBird upon the dyadic relationship

- An exploration of therapists' understanding and expectations of the implications of this mother-child relationship

- The dyadic relationship between fathers and their young autistic children

Each of the above research questions will be addressed separately.

16.2 The impact of children's significant communication difficulties upon mothers

The present study highlighted specific issues which warrant further exploration as it is not possible to transfer the findings from this study to all mothers with young non-verbal autistic children (see chapter 15.2.1, p.298). It would therefore be advantageous to carry out a further study involving a significantly larger number of participants in order to test out the theoretical insights that have been generated. This larger study could be carried out in a variety of different study sites involving mothers not known to the researcher, therefore reducing the likelihood of respondent and researcher bias. It is proposed that methods that explore not only the mothers' perceptions of the relationship, using interviews and questionnaires, but also involve an objective observation of the relationship be used, as in this study. Mother-child dyads could be identified and recruited via multidisciplinary assessment teams by letter.

16.3 The impact of PECS and EarlyBird upon the dyadic relationship

The present study highlighted the impact that PECS had upon the mother's relationship with her child when her child initiated an interaction with her using the PECS. Also highlighted was the impact of the mother's increase in understanding of her child and autism during the EarlyBird course. Both of these interventions appeared to strengthen the relationship; however, without clearly stating the research questions and exploring the specific impact of either of these strategies it is not possible to definitively attribute changes in the relationship to these. It would therefore be advantageous to carry out further studies to explore the separate impact of both of these strategies, and in order to do this outcome studies should be conducted. Curry, Nembhard & Bradley (2009) describe an outcome study as:

> *"Outcomes research examines the effects of medical care interventions and policies on the health outcomes of individuals and society" (p.1442)*

They suggest the use of both qualitative and quantitative measures in order to evaluate and promote care which will inform the development of clinical practice guidelines. Therefore, two further studies which include both qualitative and quantitative measures which measure the impact of PECS and the impact of EarlyBird upon the mother-child relationship should be conducted. Previous studies have been carried out to demonstrate the social communication effects of PECS (Carr & Felce, 2007; Lerna et al., 2012) using both pre and post intervention measures, and a very limited number of studies have measured the impact of EarlyBird on parents' understanding of autism (Engwall & Macpherson, 2003; Anderson et al., 2006). However, no studies have attempted to measure the impact of these interventions upon the mother-child

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relationship. These studies would enable policy makers and clinicians to make decisions and recommendations with regard to the most appropriate interventions and the timing of these interventions to be used with this client group.

16.4 An exploration of therapists' understanding of the implications of this mother-child relationship

The findings from this study highlighted the influences of the use and timings of specific autism strategies which are commonly used by therapists working with these children and families. Although this study did not include the views of any therapists, as this was not within the remit of this study, it would be advantageous to carry out a further study which explored therapists' understanding of the relationship difficulties that these mothers experience, and should include their perceptions of how and when to implement these interventions. This could be carried out using participatory action research which involves practitioners in the research process, from the initial design of the project through data gathering and analysis to final conclusions and actions arising out of the research in order to promote changes in thinking and practice (Whyte, 1991; Reason & Bradbury, 2006). This research design would promote a change in understanding and practice which would also benefit the children and families.

16.5 The dyadic relationship between fathers and their young autistic children

This study focused upon the relationship of the mother with her young non-verbal child; however, it did not include any research with the fathers of these young children. Although it has been demonstrated that mothers as opposed to fathers generally take on the primary caregiver role with children with a disability (Bristol et al., 1988), the impact upon the fathers of these children should also be explored in order to strengthen and promote not only the mother-child relationship but the whole family relationship. A further study which explores the fathers' relationship with their young non-verbal children would be an important continuation of this study, and comparisons could then be made between mothers and fathers in order to decide on best practice in terms of interventions. This further study could replicate the study design used in the present study in order to allow for an in-depth understanding of this relationship and generate themes which could be compared with the themes generated in this present study.

16.6 Summary

As with any study the completion of the research is not the end of the road but the beginning of a journey. This study has highlighted several further questions which would benefit from further exploration and investigation. It is my aim to seek further funding to continue this research as the implications of the findings for these families warrant further exploration and changes in practice.

In the following chapter the recommendations for practice will be discussed.

CHAPTER SEVENTEEN

IMPLICATIONS FOR PRACTICE

The previous chapter offered proposals for possible future research. This chapter will discuss the implications for practitioners and for mothers.

17.1 Introduction

The findings from this study have several implications for practice, not only for the speech and language therapy profession but for any professional engaging with mothers of young children with autism who have significant difficulties with communication and joint attention and engagement. The implications for practice are discussed below.

17.2 Implications for practitioners

Professionals, and in particular speech and language therapists, working with these families must be aware of the difficulties that these mothers may have in forming and maintaining a relationship with their young children. It has been my own experience, in line with that of other experienced colleagues, that mothers are often expected to act as therapists, especially in the pre-school years, and are given tasks to complete with their children, often on a daily basis. If these tasks are not completed, it is often difficult for the therapist to understand and rationalise why this is the case. If these mothers are struggling to develop and/or maintain a relationship with their children due to the children's difficulties,

then the timing of and support needed to implement these interventions needs to be carefully considered. Conversely, as has been demonstrated throughout this study, the increase in communication and interaction was likely to have resulted from the introduction of the augmentative communication system, and the mothers' ability to understand their children following the EarlyBird course, and resulted in an improvement in the mother-child relationship. Professionals' awareness of the difficulties that these mothers face would enable them to make clinical decisions regarding the optimum time and level of support needed to introduce specific strategies.

Raising the awareness of professionals would need to occur at a strategic as well as an operational level and the following proposals are suggested in order to promote change:

Strategic level:

- A presentation of key findings should be offered to senior clinical managers and commissioners with proposals as to how the findings will change practice. This should include key personal responsibilities and time frames.

Operational level:

- Professional training for clinicians involving presentations or workshops to focus upon present practice and proposed future practice.
- Further research project using participatory action research (Whyte, 1991; Reason & Bradbury, 2006) with clinicians in order to promote change in practice.

- Working party led by a senior clinician in which key professionals have responsibilities for implementing change.

- Dissemination to student speech and language therapists and other therapists via undergraduate university courses.

17.3 Implications for mothers

The findings from this study highlight the difficulties that these mothers experience during the early years when the focus is mainly upon the child and their difficulties and not upon the mother. It may be very difficult for some mothers to engage with interventions at a time when they are having difficulties relating to their children, and are unlikely to understand the importance or possible impact of the proposed strategies. It is therefore the remit of the therapists or clinicians to support these mothers, enabling them to engage with and understand the likely outcomes of these strategies. Failing to engage with and support these mothers may result in them being unable to carry out these interventions.

17.4 Summary

The findings from this study have been discussed throughout this thesis, and the impact of the autism-specific strategies has been proposed. In order for this study to have any impact upon the lives of these mother-child dyads changes have to be implemented at both a strategic and operational level. Several suggestions have been proposed for modifications to clinical practice and recommendations made as to how these could occur.

The following chapter will discuss my personal reflections and concludes this thesis.

CHAPTER EIGHTEEN

PERSONAL REFLECTIONS AND CONCLUSION

The previous chapter proposed changes to clinical practice for practitioners and for mothers.

18.1 Personal reflections on the research process

As a researcher I have gained a tremendous amount of knowledge, not only with regard to the subject but also with regard to the research process, methods of data collection, methodologies and ethics. This I feel will stand me in good stead for embarking on future research projects. The process of conducting such a study, where the use of both qualitative and quantitative methods of data collection allowed for a robust in-depth exploration, meant that the integration of both types of data proved to be extremely challenging. These challenges at times caused a great deal of anxiety, but, once overcome, also proved to be extremely stimulating and thought-provoking.

During the NHS ethics interview the committee highlighted the possibility of mothers or myself becoming distressed when reflecting upon and discussing very sensitive issues. As already discussed, all but one of the mothers became upset during the interview (chapter 6.9, p. 118). As a parent myself of a son with autism I did feel great empathy for these mothers and the distress they were experiencing when having to reflect upon these issues in great depth. I was however able to retain my professionalism and not allow myself to become too

emotionally involved with the mothers' situation but was still able to offer a supportive atmosphere during every encounter with mothers.

The ethics committee had suggested arranging for a clinical psychologist to be available for these mothers following the study, if the need arose. Although this was arranged, it was never requested by any of the mothers. However, during the mother-child interaction observation I found myself giving these mothers advice regarding communication and interaction strategies, as well as a considerable amount of praise in order to reassure them of their competence. Although none of the mothers specifically asked for this support, they almost covertly expected it as a trade-off in exchange for the distress they had been made to face. I obviously was very happy to offer this support and advice, but it did challenge my thoughts around professional boundaries and whether it was appropriate in my role as a researcher to give such advice and support, as this type of support would not have been available from anyone who was not a speech and language therapist.

18.2 The end of a long journey

This study has taken six years to complete and at times has been extremely challenging. The work which is included within this thesis is only a small part of the overall journey encountered to get to where I am now. It is my ambition that this study will enable a change in thinking amongst practitioners, and ultimately a change in practice. These changes will only be possible with the dissemination of the findings from this study. Dissemination to commissioners, managers and colleagues has already been discussed (chapter 17.1, p.310);

however, having prioritised time to complete the thesis it is now my ambition to prepare one or two papers for submission with the intention of relaying information regarding the mother's difficulties in forming a relationship with her child. It is the intention that this will be submitted to an autism-specific journal. A further paper will be prepared for submission to a journal specific to speech and language therapists, and with regard to implications for practice.

The very personal emotions that the mothers shared with me have resounded time and again and will stay with me for years to come. Without the honesty of these mothers this study would not be what it is. They have become part of me. I would like to end with a quote from Jill:

> *'It was just a wonderment. It really was. It was like, like I had my daughter I had her you know, because before she just didn't communicate with me. She didn't, and to me, that was the first time when she started bringing me those sentence strips, eventually, when she started communicating and she would come and put it on me and it was the closeness it just brought us together. It was definitely with me'* (Jill, NVivo line number 457)

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Appendix 1: Participant letter of invitation

Speech and Language therapy service
PCT Headquarters Building
Central Lancashire PCT
Ormskirk & District General Hospital
Wigan Road
Ormskirk
Tel: 01695 588039

Date:

Dear xxxxxx,

My name is Hilary Cowan and I am a specialist Speech and Language Therapist working with young children who have an autism spectrum disorder and their families. I work in the West Lancashire locality of Central Lancashire Primary Care Trust.

I am at present doing a PhD at the University of Central Lancashire, which will evaluate the relationship of mothers with their young child with an autism spectrum disorder who have been through the process of an assessment with a multidisciplinary team within the Central Lancashire Primary Care Trust. I hope to carry out in depth case studies of 8 mothers.

I would like to invite you to participate in my research which will, I hope, be beneficial to future parents who have to go through an in depth assessment with their child for a possible autism spectrum disorder.

I have enclosed an information sheet as well as a consent form for you to have a read through and I will contact you by telephone within the next week in order to give you the opportunity to ask any questions. However if you have any questions in the meantime please don't hesitate to contact me on the above number.

Best wishes

Hilary Cowan

Specialist Speech and Language Therapist

Appendix 2: Participant information leaflet

Study title: An evaluation of mother's relationships with their young child with an Autism spectrum disorder

What is the purpose of the study?

I am a Specialist Speech and Language Therapist working with young children who have an autism spectrum disorder and their families. This research is part of a PhD that I am doing at the University of Central Lancashire. I would like to explore mother's relationships with their young child after they have been through an assessment with a diagnostic pathway. I hope that the results of the research will inform future policy about how and when young children and their parents are managed.

I would like to invite you to take part in the research study. Before you decide to join the study, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please feel free to ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Why have I been invited?

I am hoping to include a small number of mothers (8 in total) who have been through the assessment and diagnostic pathways in Ormskirk or in Preston. All of the children will have received speech and language therapy at some point either during or following the assessment. Therefore as you have been through one of these diagnostic pathways you have been chosen to participate.

Do I have to take part?

It is up to you to decide. I will describe the study and go through this information sheet, which I will then give to you to keep. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time throughout the study, without giving a reason. This will not in any way affect the standard of care or therapy you receive.

What will happen to me if I take part?

Each mother will be involved in the research for approximately one month and this will involve you completing 2 short questionnaires, which will take between 5 and 20 minutes each. This will be followed by an interview with myself in your own home, which will last about 1 hour. I would then like to carry out a video of you and your child playing together for approximately 10 minutes and you can choose whether this takes place in the Child Development Centre that is closest to your home or in your own home. This will then be followed by another questionnaire which takes 20 minutes to complete. These will all be carried out at a time that is convenient to you and your child. It is possible that at the end of the research I will ask you whether I have truly captured your views and feelings.

Participating in these procedures will in no way affect the therapy that your child is already receiving and at no point will any therapy be withheld from your child. It is intended that this research project will be an exploratory in depth case study of each mother's relationship with her child.

Here is a diagram of how it will work

Questionnaires x 2 = 25 minutes in total
Then
Interview lasting 1 hour
Then
Video of mother and child playing together lasting 10 - 20 minutes
Then
Questionnaire lasting 20 minutes

What will happen to the video recordings, the tape recording and the written information I gain?
The video recordings, the questionnaires and the information gained during the Interview will all be treated as private and confidential. Only 4 minutes of the video recording will be used for analysis. People's names will not be used and it will not be possible to identify you in any publications I write. I will not pass on the information to any other organisation or person, however the information that I gather will be seen by my two academic supervisors from the university, including part of the video in order to ensure that I am scoring the video correctly. After the research is finished all of the data will be destroyed.

Expenses and payments
It has been agreed that expenses incurred for travel to the child development centre can be claimed from the primary Care Trust.

What are the possible disadvantages and risks of taking part?
There are no perceived risks involved in this research however you may feel that it may be upsetting to discuss your feelings in depth. I will do everything that I can to minimize this distress should it occur. Being involved in the research may also mean an extra visit to the child development centre.

What are the possible benefits of taking part?
None, however it may be that you have never had the opportunity to voice your own personal feelings about having a child with an autism spectrum disorder and would welcome this opportunity. I cannot promise the study will directly help you but the information I get from this study may help improve the treatment of families with a child with an autism spectrum disorder.

Will my taking part in the study be kept confidential?
Yes. I will follow ethical and legal practice and all information about you will be handled in confidence.

Who can I contact if I have any questions or complaints?
If you have any questions or complaints initially you can contact myself, Hilary Cowan or if you would rather speak to someone else about anything to do with the research you can contact: xxx if you have a complaint you can contact the Patient and Liaison Services on xxxx. If you become distressed there is a clinical psychologist available who can be contacted.

NHS
Central Lancashire

CONSENT FORM

Title of Project: To understand the influence of the Picture Exchange Communication System (PECS) and professional support throughout the process of assessment and diagnosis of an Autism spectrum disorder:

An evaluation of mother's relationships with their young child with an Autism spectrum disorder

Name of Researcher: Hilary Cowan

1. I confirm that I have read and understood the attached information sheet dated ………. For the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my child's therapy or legal rights being affected.

3. I understand that all information gained during the research including that from questionnaires, interviews and the video observation will be kept strictly confidential and will only be available to the researcher and her academic supervisors. Excerpts from the interview or other material gained may be made part of the final research report, however I understand that under no circumstances will my or my child's name or any identifying characteristics be included in the report.

4. I agree to taking part in the study which includes completing 2 questionnaires, being interviewed and being interviewed playing with my child.

5. I agree to my child being involved in the research and understand that he / she will be videoed playing with me.

Name of mother_____

Date _____

Signature _____

Name of person taking consent_____

Date_____

Signature _____

Appendix 4: Interview questions and prompts

Questions
1. Can you tell me a bit about your child?
2. Can you tell me when it was that you went through the process of assessment and diagnosis?
3. Can you explain to me in what way you felt that there was something different about………………. before the assessment? (Additional prompts)   Can you explain that further or give me examples?
4. Can you tell me what it was about………….. that worried you more than anything else before the assessment started? (additional prompt) How did that make you feel?
5. How did you feel about interacting with ………….. has it always been easy?   i.   Has this changed at any point?   ii.   In what way has it changed?
6. How did ……….. difficulties with communication make you feel? (Additional prompts) Did you ever feel disappointed
7. How did ……….. difficulties with interaction make you feel? (Additional prompts) Did you feel disappointed?
8. Can you explain to me whether you think that your child's difficulties affected the way you felt about him / her? (Additional prompts) can you use some words to describe the way you felt?
9. Did you receive any strategies to help with communication? (Additional prompts)   Can you tell me what difference, if any, they made? How did that make you feel?
10. Did you receive any strategies to help you interact with ………………? (Additional prompts) Can you tell me if they made a difference? How did that make you feel?
11. Do you think that the difficulties you experienced during the assessment process affected your relationship with your partner?
12. Can you describe whether you ever had any negative feelings about ………………? (Additional prompts) why do you think you had these? Was there anything that helped you overcome these feelings?
13. Can you explain whether there was anything about the way that, the professionals who were involved in the assessment or intervention behaved that made things either easier or more difficult?
14. Was there anything during the period of assessment that you think helped you to come to terms with the diagnosis better? (Additional prompts) Can you explain why?
15. Is there anything else you would like to tell me?

Appendix 5: Interview transcription for participant 4

(Questions presented in **bold**)

Okay, so just to begin with I am just going to check a few details. Can I just ask your age Sheila?

38

And are you married?

Yes

And you've just got one other child……Hazel is that right?

Yes

How old is Hazel?

She is three

Three when will she be four?

She will be 4 in July

Okay so can you remember how old Jack was when you got the diagnosis?

Oh now he was in nursery schools so he was….he must have been 3 or 3 and 1/2

Okay I'll put that down but have a look in his notes if that's okay and then I can put down the exact date that he got the diagnosis.

I think it was around the October 2007 got the diagnosis

Okay I will put possibly October 2007

Okay so how old is he now?

He is 7

7 and how many months?

7 years 3 months

Okay I will have a look in his notes of it's okay to see exactly when the assessments started and also when PECS was introduced. But he Sheila did he ever have portage. Portage workers coming to the house to help?

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No

Okay and did you attend an EarlyBird course? Can you remember when it was that you attended one?

Yes I did it was January 2008

Okay so just to begin with can you tell me just generally a little bit about Jack

Oh God, where do you want me to start?

Just anything, anything at all in general about him because I've got some quite specific questions to ask you about him and about your relationship with him

Well Jack is tall, he is blond, he's got blond hair and oh gosh what else can I say, he's very happy in himself, he's not a naughty child, he doesn't generally get upset too easily just on the odd occasion when he is fighting with Hazel (laughing). But generally apart from that he is usually a happy child. His speech and language is really very, it's very very slow, really slow but that's the only thing, besides that he's just a happy child, I am really pleased with him.

That's great and he's at nursery is that right?

Yes that's right he was in Kingsbury nursery but he is now in year two at Kingsbury. He is in the Green frog's class in Kingsbury which is the autism class and he absolutely loves it. Absolutely loves it there, really was the best thing we did for him really, because it's just so structured for him and so he knows what he's doing and he has come on in so many ways since she last saw him. He's much more confident in himself and when he is here he is asking a lot of questions and he will point things out now.

Isn't that lovely.

It is lovely to see him like that but obviously we would like him to be perfect, you want him to be…………… to do more

I know

It is frustrating (laughing) no it is really the best thing we ever did

Okay I am going to ask you a few more questions about him and about your relationship with him if that's okay

Yes

And if you could possibly be as frank as possible, if that's okay. And if you get upset it really doesn't matter it is absolutely fine. Okay so can you tell me when it was that you went through the process of assessment and diagnosis?

Well it was probably about three years ago now

Okay can you tell me what it is or what it was about Jack that you felt was different before the assessments started?

He just wasn't there, he wouldn't look at you, he wouldn't play with you as such. There were things like that and obviously he wasn't speaking. That was the first thing that we really noticed. That his speech was not coming on at all and I think that was picked up at around 18 months old. He literally, he wasn't saying anything at all not mum and dad or anything. So that was the first thing that triggered me to think that something is not quite right. So that's what started it but obviously there were other things as well but we hadn't noticed before that he didn't join in with other children and play with other children. So it's things like that but we realised that he wasn't right.

Okay was there…… what was the main thing for you Sheila?

From me it was his speech, speech was definitely the first thing it was the first thing I noticed, the main thing, just that he wasn't he wasn't speaking so yes that was definitely the first thing.

Okay so you noticed the speech but what was it that worried you the most?

Oh my goodness there were lots of things at that particular time. Jack he had a particularly difficult birth anyway. He had perinatal asphyxia at birth and was in the special care baby unit for seven days and was ventilated. And originally he was started on…. because of that and because his prognosis was not very good at all they did say to us…..they put us on to what they called a trial which we are still involved with at the moment. So I think it was always in the back of my mind from the beginning to be honest that something might not be right with him because he was always very slow at doing everything. So at walking, crawling everything he was really slow to do all these things. All his milestones, so I was constantly looking for something. But in himself he was such a happy bundle of joy when he was a baby and that we were just glad that we had him really (crying) sorry.

No Sheila please don't apologise, it's fine. No it's absolutely fine to cry most of the mums have cried and it's very difficult. The trouble is you don't often get the chance to put it forward in your own way really.

No no you tend to bury it as much as you can.

Yes yes you do so please don't apologise

So that was what, there was obviously something, so when we got the diagnosis it was kind of, like it was almost like a relief. It was like, wow now we know, now we know what it is we can do something about it. We can try and deal with it. It's been hard, it's still hard to this day.

So the things that worried you most when you were about to come and see the professionals, what was it that worried you the absolute most about him?

That he wasn't reaching his milestones. I was worried constantly obviously due to his birth and everything but it was definitely his speech. That was it I knew he wasn't talking as well as other children his own age and as soon as I knew that I thought there is something not right and that's when we got everyone involved from that point. So that's what really worried me, it was the speech. I mean the walking and everything else even although he didn't walk until he was 18 months that didn't worry me because I always knew that he would. It was the fact that he couldn't communicate.

So Sheila was it the communication or was it the speech?

The communication, the communication definitely. It was the lack of eye contact at 18 months. The lack of everything. He,he wouldn't make any effort to speak to us that's what worried me.

Yes I think that's a fair thing to say. Okay what about his interaction with you how did you feel around about that time about interacting with him. Was it easy or not?

Yes, no it was, it was easy in the sense that he liked to play, he liked to play on his own but he would let me sort of play with him to a certain extent but he got so fed up and bored easily around about that time. So yes it was okay it wasn't easy but it was okay.

So when children are communicating, and you've got Hazel now so obviously you can see what she's been like, when children are communicating with you there is an interaction there and what about that interaction although he could not speak was the interaction always what you thought it should be or not?

You mean the interaction between me and him, no there was between me and him but it wasn't, I can't think of the right word to say. There was interaction between us as in playing interaction, but speaking or talking or getting something out of him was very hard.

Okay

It was very hard

So there was a difference in the interaction?

Yes yes

So when you were playing with him and you were interacting with him, was he interacting with you?

Probably at that point not as much as what I would have liked, so no I don't think he was, so I was making all the effort, yes.

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Has his interaction with you changed at any point, rather than your interaction with him, so his interaction with you?

Yes it has, I would say in the last two years to be honest because since the EarlyBird and everything he's much more giving now. He constantly wants my attention which is good, it's lovely but then there are times when it can be a bit intrusive. A little bit, I don't know how to handle..........., he is very much, he's more interactive with me definitely.

And how does that make you feel as a mum?

Happy, I'm happy that he is like that, that he is wanting to interact with me and to play, wanting me to do things with him. I'm absolutely thrilled and made up that he is like that. But then there's a point where you know I can just be sitting watching the television and he's climbing all over me or sitting practically on me and he doesn't understand you know that he shouldn't be doing that. You know what I mean it's the lack of……

Awareness

Yes

And what do you think changed his interaction with you? What was it that helped him to understand how to interact?

I think it's just been a learning process for all of us, I mean for all of us.
In how to interact with him and understanding what his difficulties are, and I think again the school that he's been in, I think it's been a great thing for him, but………..

So are you saying it's something that you learnt?

Yes probably, as well as Jack

So was that on the EarlyBird then you learnt that?

Yes

So what was it that you learned there that made the difference?

I think it was the fact that we saw Jack for the first time, for the first time, it sounds terrible doesn't it. We saw Jack for the first time. We understood that he couldn't……….. whereas before we were chatting away talking to him and doing all sorts and it was obvious it was way too much for him so it was literally what I learned on there, was to stop it. Stop what I was doing trying to make him do things that he didn't want to do and learning that okay he is playing with a particular toy and to try and play with it with him. So that's what I've learned from that and that has just been brilliant.

Okay that's brilliant so it is the understanding is it?

Yes very much so, very much so, the understanding of his diagnosis and what it is to him, if you know what I mean

Yes I do I do, that's really helpful actually. Now you talked about the fact that his communication difficulties were the most significant worry for you, how did his communication difficulties make you feel inside?

A failure (crying)

Okay don't worry Sheila lots of mums have said that. Why do you think it made you feel like a failure?

Because I thought it was my fault I thought I was doing something wrong. That's what I thought.

Okay don't worry and did you come to realise at any point that it wasn't you?

Yes over time, again the autism course the EarlyBird course, that was like an eye-opener, and it wasn't me it wasn't me. That's what it felt like that's what it was like. That's what I needed. The worry was sort of taken away from me. Sorry sorry I'm going to be blubbing all the way through this.

No no please don't apologise it is very hard I appreciate that but I think it's important for us to try and understand what this process does to mothers. So his difficulties with communication did you ever feel disappointed?

Yes yes all the time, just that he wasn't able to communicate with us he wasn't able to………. he wasn't the same as other kids. That was awful, I was very disappointed.

Do you think that disappointment and the way that you felt almost like it was your fault did that have an effect on your relationship with him do you think?

Yes probably if I'm being honest, yes. It did actually maybe I tried too much with him, I don't know, I think it must have because it must have affected me in some way with my relationship with him and how I interacted with him. It must have. But at the time you don't realise it.

No you don't. Can you reflect back on it now easier?

Yes

Now that things are a bit further on down the line

Yes

You can

Yes

And how do you think things were then how do you think………..

I think I was trying to do too many things, trying to get in, I don't know I was just hoping that just suddenly he would pick it all up, and then he would be fine. I think I tried too hard too much for him so maybe I should have just took a step back and just looked at the bigger situation. Whereas I didn't want to. I think I was very much tunnel vision with it and I was focusing on getting him speaking and talking and everything in any way. So anything he did or said or made a sound I thought that's brilliant. So it was like I was blind to it. Just completely one-way vision and I wasn't able to think of anything else. I just tried to get him to do anything when I look back at it now I should maybe have never have been like that with him.

Yes but it's all very well with hindsight isn't it. So obviously communication for you was the biggest thing?

Definitely

What do think it is about communication, why was it communication?

I think it was just the fact that I think if you got communication with anybody in any way you can get through life. Whereas if you can't communicate then you can't………… you're never going to be able to stand up in society. You know you're not able to and that's what I…….. that's what it was for me I just needed him to and wanted him to be able to talk to me.

So was the bigger picture that you wanted him to communicate with everybody or did you want him to communicate with you?

With me (Mum answered this very quickly and was very very definite about this answer)

Okay why you in particular?

I don't know (crying) I suppose really you want to be told that you are a good mum, I suppose.

And do you think when your child is communicating it shows you that you are a good mum?

Yes definitely, that's just my thing that's how I think

I think that's a very very important thing to say because I think that's how a lot of mums feel actually. If your child is not communicating……..

Yes where do you go, it's like what do you do if he isn't or what do you…….. you know it's a hard one (crying)

Okay so we talked about the communication what about the difficulties with interaction coming from him. The difficulties with interaction from him with you, how did that make you feel?

Again very very disappointed. I didn't think I was doing things right. I thought it was my fault, everything that I felt at the time definitely.

So you've obviously been able in your own mind to be able to rationalise that now?

Yes

What made you realise that it was not your fault?

I think when…. it sounds terrible…… it was literally when we met yourself and Val and Rhiannon, the things you were saying like that Jack was not doing at the time you know the typical behaviour like lying on the carpet, the things he was doing you just made it sound like well we were not the only……. that was more helpful than anything, it was like, honestly it was just like a big release it was really at the time, I never thought, it was like a big weight had been lifted off my shoulders.

Was that during the assessment?

Yes but before that actually when we got the speech and language therapy in, I mean they were giving us things to do with Jack. Jack was making a little bit of progress. It's just that it made me feel well you know we are going to get somewhere or he will be all right. It was definitely when we got the professionals and that I suddenly realised it wasn't me, that he did have something, some sort of problem or difficulty which obviously I was probably thinking no no it's going to be all right and pushing it to the back of my mind thinking he was just a little bit slower than other kids. You know he'll be fine he'll catch up. But it was when speech and language therapy came in originally and then obviously we got yourself and Val involved with the EarlyBird and the assessment that I realised then. I thought no it's not me it's… this is how he is and it's not me, I can do it, all we can do is help him. So at the time honestly it was the best thing at the time.

Well that's very good to hear and do you think that Jack's difficulties affected the way that you felt about him?

No no no I loved him then so no it didn't.

Okay that's great so now thinking about communication so we talked about communication and how that was very difficult. What strategies did you receive to help him with his communication?

It was literally beginning with the PECS it was the PECS system which was…… At the time, I didn't think it was going to work, I really didn't think… I didn't think it would work it was really my mindset at the time. I thought what are we doing this for which sounds silly. But it was when he actually began to start to use it and make sentences with it and I thought hang on a minute this is fantastic because he was actually speaking some words in an appropriate manner and I remember thinking it was fantastic, absolutely fantastic.

So what was it about it?

I think it was just that it was Jack being able to concentrate and look at the pictures and understand what they meant, that was what got me because he hadn't, he had never really done anything like that or he'd point. He did have books and he'd say car but it was never anything like a sentence or any formation it was never anything like that so it was definitely that PECS.

So we talked a bit about at the beginning about speech and and then we decided it wasn't actually speech it was communication so what was it about the PECS that made a difference to you?

To me it was just that he was able to understand, understand what he wanted and he could actually physically use the PECS system to make himself known what he wanted. So that's what it did for me.

Okay that's really good. So he started making sentences up how did it make you feel as a mum?

Brilliant absolutely brilliant knowing that he could actually do a sentence, it was just absolutely marvellous.

So if he'd been able to just do the sentence but not actually brought it to you would that have been the same if he had just said it to the PECS book and not actually brought it to you?

No no it wouldn't

So what was it then about……….

I think it was just the interaction. It was the interaction between us and and the fact that he was actually coming up and asking me appropriate things, you know what I mean?

Yes yes I do absolutely, so it was the interaction with you?

Yes definitely

And that made you feel?

Fantastic, brilliant I felt like I was getting somewhere with him it was just fantastic.

Any idea of why it made you feel fantastic?

I think because again it's coming down to me feeling like a failure in some sort of way. I felt I was not doing things right but now I am going to be okay things can be all right. I just didn't feel like I've messed it up.

Okay that's really helpful. Did you receive any strategies to help you with interaction with him?

I can't remember actually

What about the stuff you did through EarlyBird. Did that help?

Yes yes playing the games definitely. That really really did help. So finally we could get him to do something, because that was like, he never ever did anything like that it was very one sided when he was little so…..

Okay so what made the difference then and why did it suddenly become………….

I think it was just again it was the learning process, it was learning how to communicate with him and interact with him and getting him to interact with us it was all, it was all of it. It helped me to realise that I can't just shout things after or say things to Jack you know in a big massive load of words cause he's obviously not understanding so it helped me to understand the fact that I had to strip it right back and just use one or two words. And at the time he was reacting to it and it actually helped you know. Passing the balloon to us and passing the toys to us. That was brilliant it was like the best thing ever. I really looked forward to going because it was something new and I learned something new every week.

Okay that's great let's move on to something slightly different now do you think the difficulties that you experienced during that time of assessment and diagnosis did that affect your relationship with your husband?

Probably yes, obviously we were very stressed about it, but the assessment side of it because at the end of the day I mean I didn't want him to, it sounds terrible, I didn't want to be told my child was autistic but we were both stressed. But in our relationship it was just a little bit, we didn't speak, we talked about it but it was like okay it was happening and there is not much we can do. Besides that there was just the nonspeaking side of things like "are you all right". It was just that lack of communication between the two of us. But I think both Stephen and I we both wanted to know what was wrong so even although we weren't speaking to each other when the assessment was going on you know we realised obviously that it could be possibly this is what it is but we never actually said it to each other. It's sad, but now it sounds funny.

And what about now are things easier, can you talk about it now?

Absolutely, anything I mean sometimes Jack's doing something that he shouldn't, misbehaving and you have to think what is the reason behind this, it you know there's got to be something, and you shout and then you'll have to remember back to look at why he is behaving in that way and it's only then that one of us will go, come on, hang on a minute it might not be that, let's see what it is. But now yes we can speak to each other about it no problem at all.

Great okay can you tell me whether you have ever had any negative feelings about Jack?

Negative… probably yes, yes to be honest… (crying)……..

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And again that is what a lot of other mums do say to be honest. You are being very honest. Please don't worry. Do you think you could explain that a little bit more?

Just…… I can't think of the words….. I think at the time, I just felt really, I just felt disappointed, it was my fault, I just felt very disappointed and very angry. I think that was the biggest thing just felt disappointed because he wasn't the same as other kids. Why me.

Again that's perfectly normal to feel like that

But nobody ever speaks about it, you don't speak about it.

I know people don't speak about it and that's the thing that is difficult because people don't talk about negative feelings. You know as a mother you are supposed to feel good of all time and you know it just isn't the case all the time

Definitely not, it certainly wasn't the case with me, I'm sorry.

No no please don't apologise. Were there any other feelings that you had, any other word to describe how you felt?

No, I think it would be mainly angry, disappointed, I felt like I was a let-down.

What about now?

I still have some feelings like that.

Do you, that you let him down?

Sometimes, sometimes when I get angry with him, when I get frustrated with him I feel like it's my fault and I should not be like that.

But all mums get angry some time with their children

Now I know but I just think I should be a bit more understanding with him, sometimes definitely, and it's only when I have shouted and made him go up to his room that I then think, it's that feeling when I calmed down I think why did I do that he doesn't understand what he's done and I'm just ranting off and I feel very disappointed in myself. It's not his fault it's mine.

But I do think lots of mums whether your child has a disability or not we all flip at times and just because your child has a disability that is no reason why you shouldn't feel like that because sometimes we are pushed to our limits.

But we still feel guilty. Once I've done it I think my God I should never have done that even although he probably has done something wrong

Yes absolutely………., what about thinking about the professionals who were involved around the time of assessment and diagnosis because your

assessment lasted around about 16 weeks. Was there anything about the way that the professionals behaved that made it either easier or more difficult?

Probably I'd say easier, because I felt that I could talk about it and it was not like a taboo subject and pushed to the back of my mind, I felt easier once the professionals were involved. They made me feel at ease even although it was a very difficult time throughout the assessment because we did not want that diagnosis. Both me and Stephen would tell you that now and at the time we were like it is going to be all right. So no everyone was fantastic and made us feel that you know you are not the only people going through this with a child with a problem.

Some places, where the assessment is carried out, it lasts a week

Oh my word

You are seen by individual people and then you get feedback at the end of the week and then obviously the assessment pathway here is quite a lengthy one where you always see the same group of professionals and there is that therapy throughout so you have the PECS therapy. Do you feel it would have made a difference had you had a shorter assessment

Definitely

In what way?

I think it wouldn't have, they would have felt like massively hurried if it only took a week, and you are seeing a different professional everyday, I think that would have been more stressful. To be honest I wouldn't have liked that.

So what was it about the way that the pathway was run that made it easier for you?

Definitely because we saw the same people for the 16 weeks and it was definitely for 16 weeks, it wasn't just here you go we are going to a tell you tomorrow that your child is autistic, it was a long process where you were looking at it from all different angles of Jack's behaviour and obviously his communication and his speech. The way he was interacting with everyone. It was the fact that it was a long time and we had time to adjust to it as well, because that was really important.

So the time was important?

Yes because those 16 weeks, the first few weeks you are thinking you know, this is not going to be and then you realised as time went on because you are with the same group of professionals, you think hang on, it just made us feel better in ourselves over a longer period and it was not just a quick here you are we are seeing him today and tomorrow you will get the diagnosis. So it was brilliant the way it happened.

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Do you think there was anything during that period of assessment that helped you come to terms with the diagnosis when you eventually got it?

It was the fact that you know, it was the fact for me that the professionals were saying to me about Jack's behaviour, the way he was, fitted into this triad and because of that it made me realise, it made me feel that I was not alone, it sounds silly but I realised that I wasn't alone and that there is definitely something wrong, it made me feel better over the long run. I'd say it was about halfway through the assessment period that I realised that Jack is definitely going to be autistic. Obviously when we came away…………

So when you came for your diagnostic feedback was it a shock to you?

No it wasn't a shock at all because of the nature of the way the assessment had been carried out and the amount of time it took, and the things that you were saying that Jack was doing, that we realised Yes hang on a minute he does do that. It made us realise that this is definitely a diagnosis of autism. So no it was not a shock at all at the end of the 16 weeks when we got that diagnosis I think we were expecting it.

Yes I think a lot of people at the end of the lengthy process are expecting to hear………..

Yes I think it's just the learning side of it as I said before, because every week we were learning something new about Jack, you know the way he was playing wasn't right, it was the whole process.

So is it the fact that you are learning throughout the process of assessment that things are not quite right that helps you come to terms with the fact that he has a diagnosis?

Yes definitely that's right that's absolutely right

Okay so just the final question, thinking about your relationship with Jack, how would you describe your relationship with him now?

Very loving, caring between the two of us, he is more interactive with me and I am with him. I just feel I feel a lot better about it. I feel a lot better about my relationship with him. I feel finally I have come to terms with it, that sounds terrible, but like finally I have come to terms with it, I know it's taken me a long time.

So that's your relationship with him now how would you have described your relationship with him around the time of assessment and diagnosis?

Probably very strained really, very tentative with him, I was a little afraid. I didn't know how to handle him or whether I was doing things right, if it was me was it my fault. At the time I didn't feel as much love as I do now, it sounds terrible,

No that doesn't sound terrible so it's what you are saying that you feel better now, what's that because of?

I don't know I think it's just because of acceptance of the way he is over time. I don't think I was very accepting of the way he was.

So is it partly you coming to terms with it?

Yes definitely

And was it helped at all by the fact that he is now more interactive with you?

Certainly, yes absolutely you know that I'm getting something back from him is absolutely brilliant, absolutely.

As it is important as a mother

It certainly is

Okay Sheila thank you very very much helping

Appendix 6: Reflexive memo following interview: participant one

- Very little experience of disability prior to child being born. Mentioned a friend with child with ADHD but felt sorry for mother not the child. Felt that mother was afraid of stigma. Saw a programme once about autism.

- Found time around diagnosis very difficult in one way but also very reassuring as she felt no one was listening to her prior to this. She felt embraced by members of the team. Was glad that it lasted some time as she felt it was important to not be rushed and to have other things in place prior to diagnosis.

- Worst feature for Mum was lack of interaction and communication.

- Interaction initially was very difficult with child. Changed when she received PECS where child had to approach Mum for things that then changed Mum's attitude to child. Play therapy from nursery officer and portage worker also helped mum to understand how to play with child. Get down to her level.

- Mum felt very disappointed and embarrassed to have a child with comm. diffs. Felt a terrible stigma. She felt very alone and in a wilderness.

- Difficulties with interaction definitely affected the way that mum felt about child. She felt rejected and became a child herself. "if you won't communicate with me I won't bother to communicate with you".

- Best strategies were PECS to promote interaction, play therapy to increase interaction and EarlyBird where Mum began to understand how the child thought differently.

- once interaction / joint attention increased / improved mum felt better about child and was more able herself to interact.

- Felt that professionals were caring and kind but also were honest. Enjoyed getting to know professionals over some time and felt safe with them to take some of the burden.

- Has had lots of negative feelings towards child.

- Now has a greater understanding about disability and autism. Was able to care for an autistic man on the ward recently which made her feel good about herself and her ability.

Words used to describe feelings

Wilderness
Stigma
Couldn't interact with me
Heart Breaking
Angry
Not being a proper mother
Detachment
Betrayal

Broke down barriers between her and her child
Revelation
Wonderment

Appendix 7: Maternal behaviours coding scheme

Affect

5 = Extremely warm, kind tone of voice with very enthusiastic animated and cheerful mood showing much enjoyment and pleasure

4 = Warm, kind tone of voice with enthusiastic animated and cheerful mood showing enjoyment and pleasure

3 = Indifferent mood, neither positive nor negative

2 = Angry, hostile tone of voice and negative affect. Some expression of displeasure, disapproval, criticism or irritability

1 = Very angry, hostile tone of voice and negative affect. Significant expression of displeasure, disapproval, criticism or irritability

Quality and amount of physical contact

5 = Extremely warm, positive and very supportive physical contact

4 = Warm, positive and supportive physical contact

3 = Minimal amount of physical contact or physical contact that lacks definite quality

2 = Negative physical contact or none observed

1= Very negative physical contact used to reject child

Quality and amount of visual contact

5 = Mother uses consistent appropriate eye contact and is always down at child's level

4= Mother uses mostly appropriate eye contact and is down at child's level most of the time

3 = Some eye contact is used but may be inconsistent

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2 = Very little eye contact and not down at child's level

1 = No eye contact and mother never at child's level

Quality of language

5 = Very appropriate, very positive language including commenting, repetition and praising

4 = Mainly appropriate, positive language including commenting, repetition and praising

3 = Mixture of both positive appropriate language and some inappropriate language

2 = Inappropriate language including questioning and directing

1 = Very inappropriate language using only questioning and directing

Quality and amount of gestures and non-verbal clues used to support understanding

5 = Mother uses many strategies consistently throughout session including pointing, showing or other gesture and/or other visual strategies such as visual symbols to engage child and support child's understanding

4 = Some non-verbal strategies used but not used consistently

3 = Some non-verbal strategies used but lacking in consistency and quality

2 = Minimal use of non-verbal strategies

1 = No non-verbal communication behaviours used despite the child showing obvious signs of struggle to understand

Mother demonstrates flexibility and creativity to engage her child

5 = Mother shows consistent flexibility in structuring the environment and her actions and consistently follows her child's lead or cues

4 = Good flexibility used but may not be used consistently

3 = Some flexibility but may be lacking in consistency and/or quality

2 = Minimal use of flexibility

1 = Mother rigid, inflexible or inconsistent and insistent on following her own lead

Percentage of time spent in joint attention =

Comments on competence and confidence

Comments on quality of attachment

Comments on reciprocity between mother and child

Appendix 8: Child behaviours record

Affect ☐

5 = Extremely happy, pleasant and cheerful mood showing much enjoyment and pleasure

4 = Cheerful mood showing mainly enjoyment and pleasure

3 = Indifferent apathetic mood, neither positive nor negative

2 = Withdrawn and depressed mood

1 = Very angry, hostile

Quality and amount of physical contact ☐

5 = Extremely warm, positively approaches mother and enjoys physical contact

4 = Some approaches but on their own terms

3 = Minimal amount of physical contact or physical contact that lacks definite quality

2 = No physical contact

1= Very negative physical contact used to reject mother

Quality and amount of communicative gaze ☐

5 = Child uses consistently appropriate eye gaze in order to engage mother

4= Child uses eye gaze most of the time

3 = Some eye gaze is used but may be inconsistent

2 = Child uses very little eye gaze

1 = No eye contact with mother

Quality of communicative intentions

5 = Language and communication used appropriately for chronological age to communicate with mother (including vocabulary and phrase length)

4 = Child makes good attempts to communicate but communication may be inconsistent

3 = Some attempts to communicate but may be inconsistent or may lack quality

2 = Minimal attempts made to communicate

1 = No attempts made to communicate

Non-verbal communication acts

5 = Child consistently uses pointing, showing, other gestures or PECS symbols to engage mother and support his/her expressive communication

4= Child makes good attempts to use non-verbal communications but may be inconsistent

3 = Some non-verbal actions used but may be inconsistent or may lack quality

2 = Minimal non-verbal acts used

1 = No non-verbal communication behaviours used

Appendix 9: Observations to be made during mother-child interaction

During the observation of mother-child interaction specific behaviours which were taught on the EarlyBird course were observed and included:

- Quality and amount of visual contact and the mother's ability to get down to the child's level (a high score would indicate that the mother was able to engage her child by being face-to-face)
- Quality and appropriateness of language (a high score would indicate that the mother was able to use very appropriate language which was pitched at the child's level of understanding. Very positive language includes commenting, repetition and praising)
- Quality and amount of gestures and non-verbal clues used to support understanding (a high score would be awarded if the mother used many strategies consistently throughout the session including pointing, showing or other gesture and/or other visual strategies such as visual symbols to engage child and support child's understanding)
- The mother's ability to be flexible and creative to engage her child in an activity (a high score would indicate that the mother was very flexible and was able to engage her child throughout the session)

Participant 4   Video of M° child interaction 13/5/10

Received Q's

Mum slightly awkward with child

Constantly directing child

She took the lead most of the session

Down at his level but not face to face

Used some physical prompting to gain attention

Lots of questions :- Is that for mummy, whats that.

Child started to sing what he was doing but M° did not join in.

Didn't give any choices.

Not much physical contact.

Used a gesture to comment on hat.

quing him in with initial sound of word

Appendix 11: Completed contact summary sheet: participant six

Contact summary sheet
(To be completed immediately following contact)

Type of contact (e.g. phone, home, CDC) ___Home___

Contact date: _20/9/10_   Today's date: _27/9/10_

Written by: _Hilary_   Mother / Child code ___Participant 6.___

1. What were the main issues or themes that struck you in this contact?

Mother very honest. Keen to get things off her chest.
Daughter has Aspergers.

2. Summarize the information you got or did not get on each target question.

Question	Information

Desperate for more information about Aspergers.
School doesn't believe mum
Relationship changed when she had another child ? because
she needed to feel needed + now had another baby who was
much more responsive.
No support during or after diagnosis

3. Anything else that struck you as salient, interesting, illuminating or important in this contact? Attach a theme to each point (number point in text.

Page	Point	Theme

4. What new (or remaining) target questions do you have for the next contact?

5. Were there any non verbal behaviours you want to comment on?

Mum very calm. Didn't get upset.
I didn't feel that there was nearly the same depths of despair
in this mum compared to all others.

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Appendix 12: Results from early and later emotions PSI

Attachment

Competence

Spouse

Depression

Child domains

Child mood

Reinforces parent
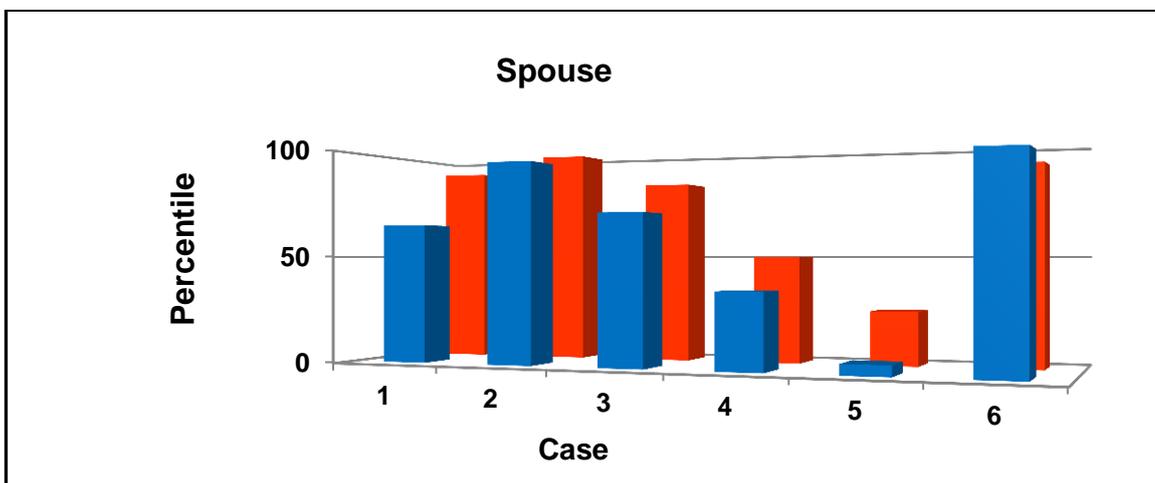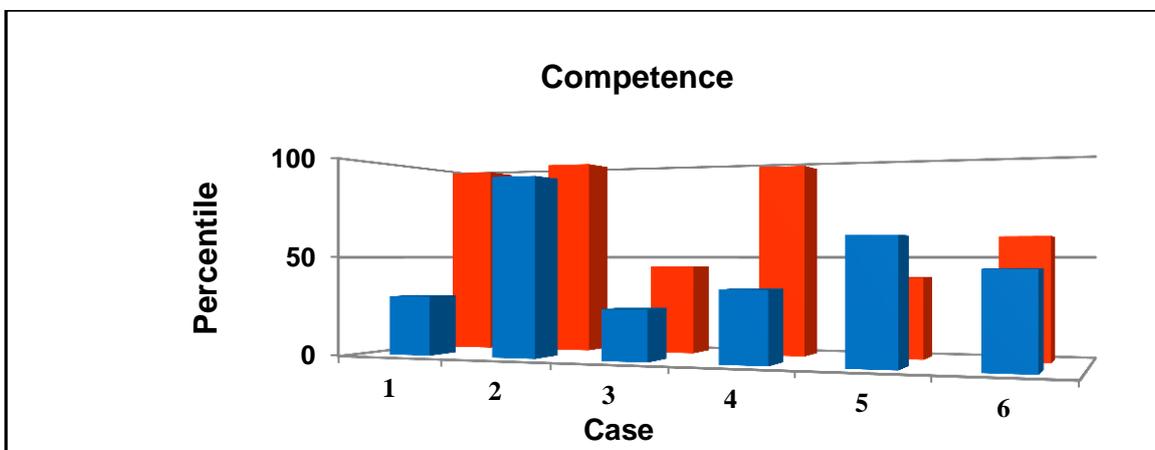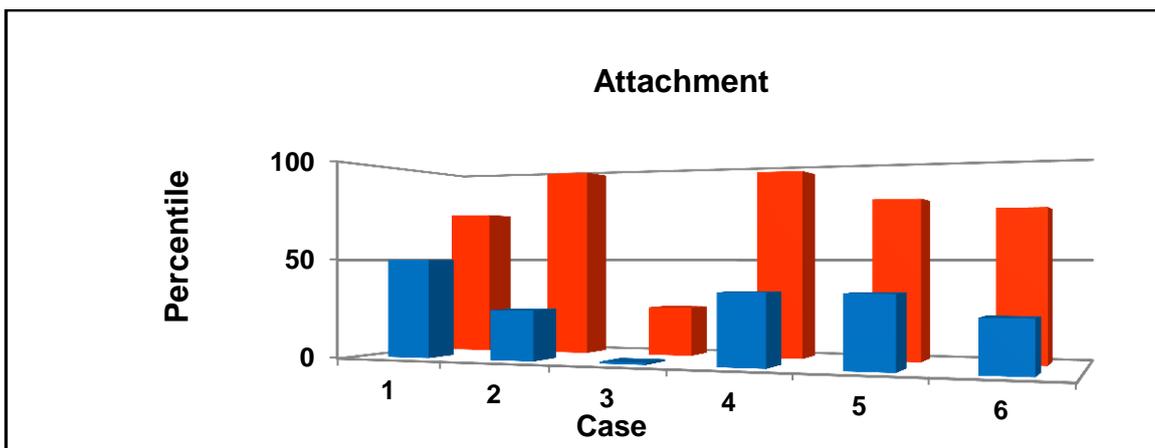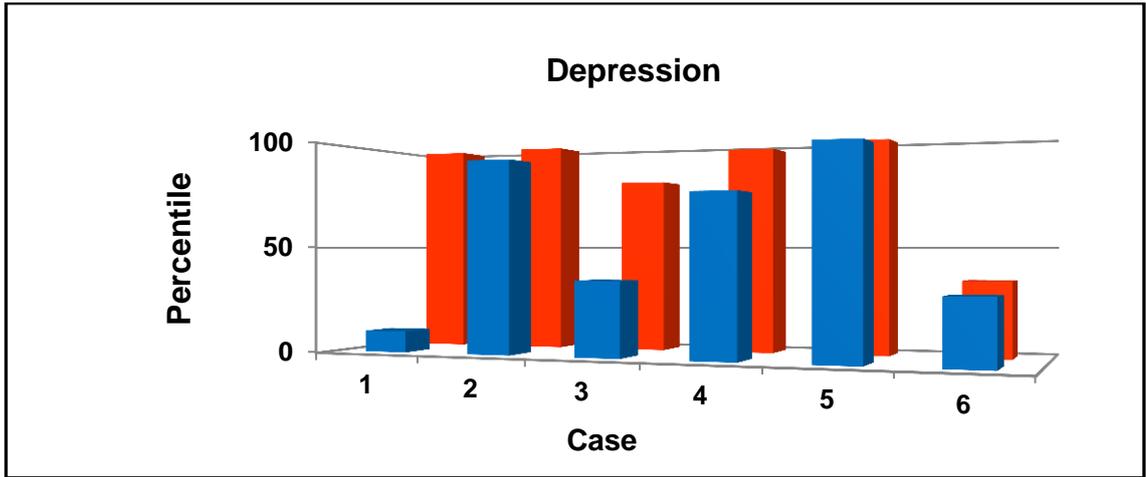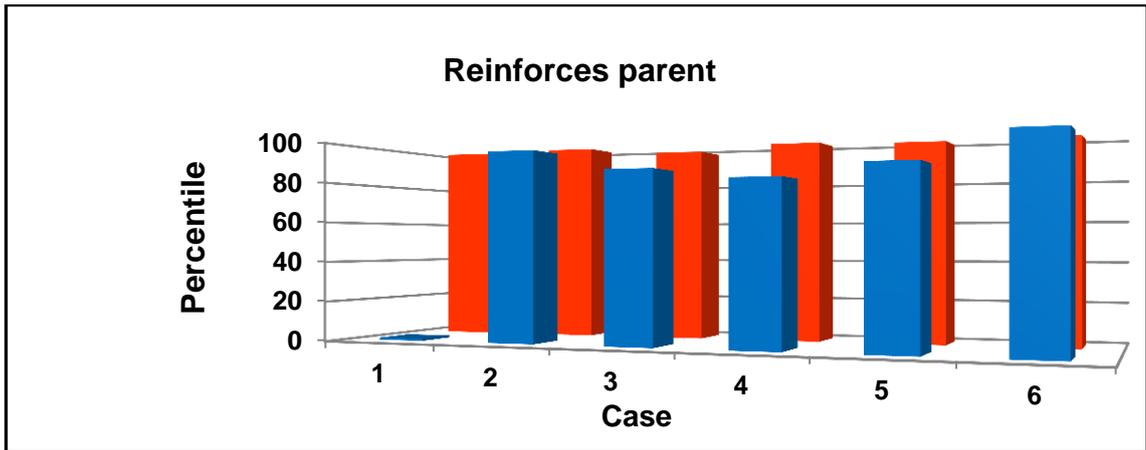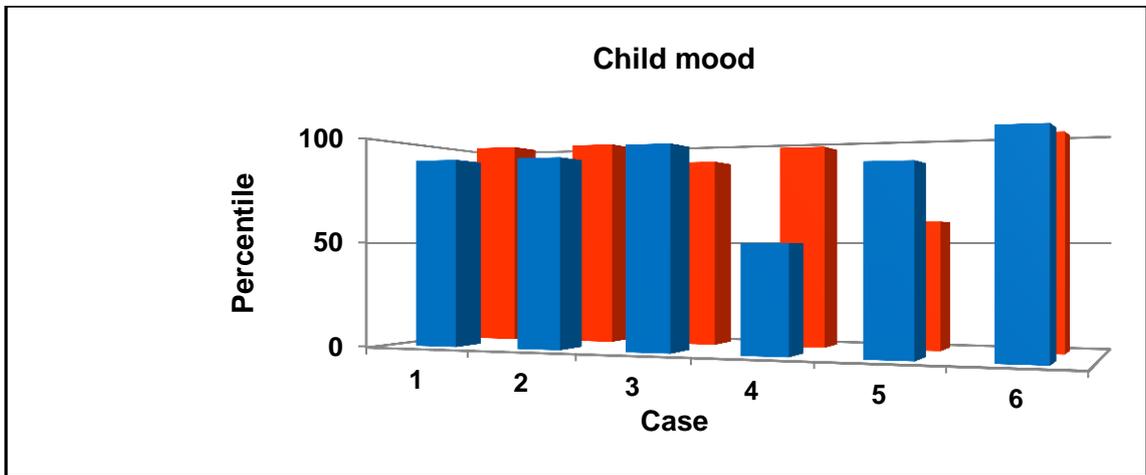
■ **Early emotions**   ■ **Later emotions**

Appendix 13: Maternal and child domain descriptions from the PSI (Taken from the Parenting Stress Index Third edition: Professional manual: Abidin 1995)

Maternal domains

Attachment (AT)

High scores on this subscale suggest two possible sources of dysfunction:

- The parent does not feel a sense of emotional closeness to the child.
- The parent's real or perceived inability to observe and understand the child's feelings and needs accurately

Competence (CO)

High scores will be found among parents who do not find the role of parenting as reinforcing as they had expected; these parents are often overwhelmed by the feeling that 'this child is more than I bargained for' and 'I am not sure I would have children if I had to do it over again'(Mouton & Tuma, 1988).

Depression (DP)

High scores on this subscale are suggestive of the presence of significant depression in the parent.

Spouse (SP)

High scores on this subscale are those who are lacking the emotional and active support of the other parent in child management.

Child domains

Reinforces parent (RE)

Parents who score high in this domain do not experience their child as a source of positive reinforcement and the interactions between the parent and child fail to produce good feelings by the parent about themselves. The parent may feel rejected by their child.

Child mood (MO)

High scores in this domain are associated with children whose affective functioning shows evidence of dysfunction and who are unhappy, depressed or frequently cry.

Appendix 14

Flowchart produced by NICE 2011 for the assessment and diagnosis of autism

Referral

Regression

- Refer children younger than 3 years to the autism team if there is regression in language or social skills.
- Refer first to a paediatrician or paediatric neurologist, who can refer to the autism team if necessary, children and young people:
  - older than 3 years with regression in language
  - of any age with regression in motor skills.

Concern about signs or symptoms but no regression

Consider referring children and young people to the autism team if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms (see tables 1–3 on pages 14–19). Take account of:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family
- the level of parental or carer concern and, if appropriate, the concerns of the child or young person
- factors associated with an increased prevalence of autism (see table 4 on page 20)
- the likelihood of an alternative diagnosis.

Insufficient concern to refer immediately, or referral declined

- If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting.
- If the parents or carers (or when relevant the child or young person) prefer not to be referred to the autism team, consider a period of watchful waiting.

Concerns raised, but no signs, symptoms or other reasons to suspect autism

- Use professional judgment to decide what to do next.

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary **or**
- referring to another service. That service can then refer to the autism team if necessary.

If you remain concerned about autism, reconsider referral.

Explain to parents or carers (and if appropriate the child or young person) what will happen on referral to the autism team or another service.

Referral letter to the autism team

Include:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms.

Include if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see table 4 on page 20)
- relevant medical history and investigations
- information from previous assessments.

Deciding on assessment

- When a child or young person is referred, at least one member of the autism team should consider whether to carry out:
  - an autism diagnostic assessment **and/or**
  - an alternative assessment.
- Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

Children and young people:
- older than 3 years with regression in language
- of any age with regression in motor skills.

Regression in language or social skills in a child younger than 3 years.

All other children who have been referred to the autism team, including those referred back from a paediatrician or paediatric neurologist.

- Refer first to a paediatrician or paediatric neurologist, if this has not already happened.
- The paediatrician or paediatric neurologist can refer back to the autism team if necessary.

When deciding whether to carry out an autism diagnostic assessment, take account of the following:
- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person
- factors associated with an increased prevalence of autism (see table 4 on page 20)
- the likelihood of an alternative diagnosis (see table 5 on page 20).

If there is insufficient information to decide whether an autism diagnostic assessment is needed, gather any available information from healthcare professionals. With consent from parents or carers (and the child or young person if appropriate), seek information from schools or other agencies.

If there is still uncertainty about whether an autism diagnostic assessment is needed, offer a consultation to gather information directly from the child or young person and their family or carers.

Carry out an autism diagnostic assessment.

Assessment

General principles

- A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.
- The autism case coordinator should:
  - act as a single point of contact for the parents or carers, and if appropriate the child or young person being assessed
  - keep parents or carers, and if appropriate the child or young person, up to date about the likely time and sequence of assessments
  - arrange information and support for parents, carers, children and young people
  - gather information relevant to the autism diagnostic assessment.

- Start the autism diagnostic assessment within 3 months of the referral.
- Discuss with the parents or carers (and if appropriate the child or young person) how information should be shared throughout the autism diagnostic assessment, including communicating the outcome. Take into account, for example, the child or young person's age and ability to understand.
- With consent from parents or carers (and the child or young person if appropriate):
  - seek a report from the pre-school or school if one has not already been made available
  - gather any additional health or social care information, including results from hearing and vision assessments.

Consider which assessments are needed

Consider which assessments will be needed to construct a profile, for example:

- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills

- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
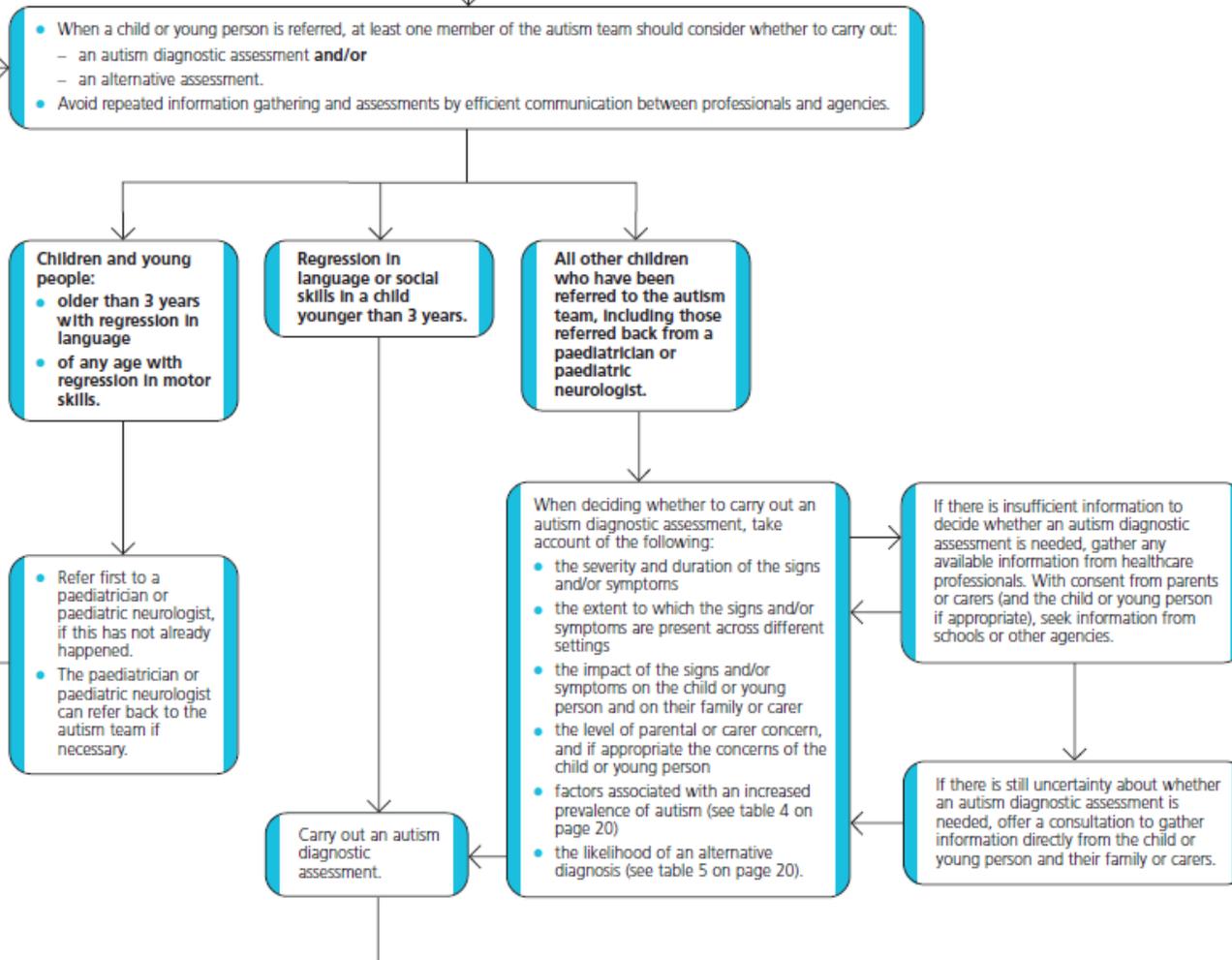- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills.

The autism diagnostic assessment

- Include in every autism diagnostic assessment:
  - detailed questions about parent's or carer's concerns (and if appropriate the child's or young person's concerns)
  - details of the child's or young person's experiences of home life, education and social care
  - a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
  - assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
  - a medical history, including prenatal, perinatal and family history, and past and current health conditions
  - consideration of differential diagnoses and systematic assessment for conditions that may coexist with autism (see pages 20–21)
  - development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
  - communication of assessment findings to the parent or carer and, if appropriate, the child or young person (see page 12).

- Perform a general physical examination and look specifically for:
  - skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
  - signs of injury, for example self-harm or child maltreatment (see 'Related NICE guidance' on page 22)
  - congenital anomalies and dysmorphic features including macrocephaly or microcephaly.
- Consider differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations (see table 5 on page 20).
- Consider whether the child or young person may have a coexisting condition (see table 6 on page 21), and if suspected carry out appropriate assessments and referrals.
- Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:
  - genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability
  - electroencephalography if there is suspicion of epilepsy (see 'Related NICE guidance' on page 22).
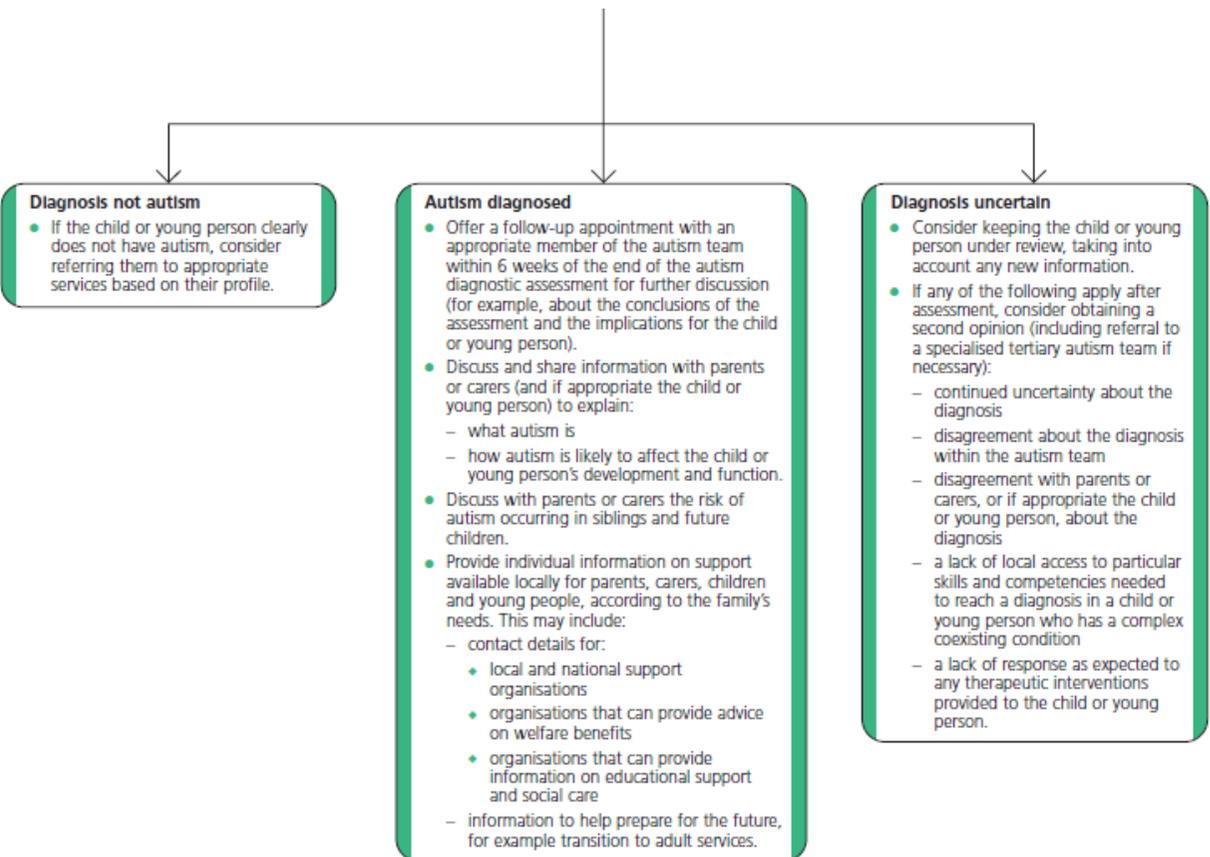
Diagnosis

If there are discrepancies between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider gathering additional information from other sources and/or carrying out further autism-specific observations in different settings.

Diagnosis

- Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.
- Do not rely on any autism-specific diagnostic tool alone to diagnose autism.
- Be aware that in some children and young people there may be uncertainty about the diagnosis of autism, particularly in:
  - children younger than 24 months
  - children or young people with a developmental age of less than 18 months
  - children or young people for whom there is a lack of available information about their early life (for example some looked-after or adopted children)
  - older teenagers

- children or young people with a complex coexisting mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder), sensory impairment (for example severe hearing or visual impairment), or a motor disorder (such as cerebral palsy).
- Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems.
- Consider any potential risk of harm to, and from, the child or young person and take appropriate action.
- Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services.

Communicating the results from the autism diagnostic assessment

- After the autism diagnostic assessment, discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers (and if appropriate, the child or young person). Explain the basis of conclusions even if the diagnosis of autism was not reached.
- Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.
- Provide parents or carers (and if appropriate, the child or young person) with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.

- Share information, including the written report of the diagnostic assessment, with the GP.
- With parental or carer consent (and the consent of the child or young person if appropriate), share the profile with key professionals involved in the child's or young person's care, including those in education and social care.
- With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

Diagnosis not autism

- If the child or young person clearly does not have autism, consider referring them to appropriate services based on their profile.

Autism diagnosed

- Offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism diagnostic assessment for further discussion (for example, about the conclusions of the assessment and the implications for the child or young person).
- Discuss and share information with parents or carers (and if appropriate the child or young person) to explain:
  - what autism is
  - how autism is likely to affect the child or young person's development and function.
- Discuss with parents or carers the risk of autism occurring in siblings and future children.
- Provide individual information on support available locally for parents, carers, children and young people, according to the family's needs. This may include:
  - contact details for:
    - local and national support organisations
    - organisations that can provide advice on welfare benefits
    - organisations that can provide information on educational support and social care
  - information to help prepare for the future, for example transition to adult services.

Diagnosis uncertain

- Consider keeping the child or young person under review, taking into account any new information.
- If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary):
  - continued uncertainty about the diagnosis
  - disagreement about the diagnosis within the autism team
  - disagreement with parents or carers, or if appropriate the child or young person, about the diagnosis
  - a lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition
  - a lack of response as expected to any therapeutic interventions provided to the child or young person.

<u>Appendix 15: Instructions for carrying out the video analysis</u>

This video analysis of mother-child interaction has been devised as part of a PhD study which is aiming to explore mothers' relationships with their young children with autism. It is one of several methods of data collection being used in this research and is not being used as part of the child's therapy. The essence of the analysis is to observe the mother's behaviours and interactions towards her child; however, in order to do this it is essential to observe what behaviours the child is displaying and how these behaviours have an effect upon the mother. Therefore child behaviours are also observed and scored. Instructions as to how to carry out the analysis, the specific toys to be used, the analysis sheets needed and the electronic equipment needed for videoing the session are all given.

- Position the selected toys in a room, which is distraction free prior to the mother and child entering the room. The toys included are listed.
- Ensure that the video camera is charged and has a new tape in it and is out of reach of the child.
- Explain to mother that the session is being recorded as part of a PhD that she has agreed to participate in and is not part of their treatment. Ask her to play with her child in the way she normally would and reassure her about the video recording.
- Video the mother and child interacting in a natural way with toys for 20 minutes.
- Thank the mother and child for participating.
- Import the full 20 minutes of video into NVivo.

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- Wind the tape forward for exactly 8 minutes into the recording, which will have allowed time for the mother and child to settle into the session.

- Mark the video recording on NVivo for 4 minutes, which will be used for analysis.

- The 4-minute section will be viewed at least 4 times by the same observer.

- It is essential that prior to scoring the observations the examiner is familiar with the behaviour analysis sheet and with the definitions of the behaviours to be observed.

- In the initial viewing code the mother's behaviours using the maternal behaviours analysis sheet.

- The second viewing will be used to code the child behaviours using the child behaviours analysis sheet

- The third and fourth viewing will be used to record the mean length of utterance of both the child and the mother, and to make any further observations not already made.

- Any comments, thoughts or feelings of the observer should be recorded in the additional comments section under each behaviour.

- Following the coding the codes will then be transferred onto the analysis sheet.

The following toys (which are kept in a large box) should be laid out in an inviting manner before the child enters the room

Carousel
Stacking toys
Pretend food and tea set
Doll with blankets, bottle, toothbrush and hairbrush
Toy cars
Inset jigsaw
Fuzzy felt
Car run
Posting toys
Toy telephone
Selection of books

1. **Record sheets needed:**

   - **Maternal behaviours record sheet**

   - **Child behaviours record sheet**

Appendix 16: Chain of evidence

27.11.08 Wrote protocol for carrying out video analysis

2.1.09 Favorable opinion from ethics committee

12.1.09 Resubmitted to ethics committee

12.1.09 Updated mother and child behaviours to give a fuller explanation of the behaviours

12.109 Completed analysis for codes sheet

12.1.09 Emailed all video analysis documents to supervisor

19.1.09 Completed GANNT chart for following year

19.1.09 Started to compile chapters list

14.2.09 2 colleagues sent the video analysis to complete

15.2.09 Ethics approval received

16.2.09 R & D approval received

18.2.09 Applied for university ethics approval

13.2.10 Applied for major amendment to ethics

24.2.10 Amendment granted from ethics committee

27.2.10 Contacted 2nd mother from main study who agreed to participate

4.3.10 Visit arranged to interview mother

10.5.10 & 11.5.10 Visited 3 mothers to carry out interviews

13.5.10 3 mothers attended CDC for video of mother child interaction

31.8.10 Completed GANNT chart for 2010 / 2011

1.9.10 Transcribed interview for participant 3

15.12.10 Paper rejected by Autism journal with accompanying comments

16.12.10 Reflected upon the comments made by reviewers and came up with ways to modify my study

18.12.10 External supervisor contacted supervisor and has asked to meet with me and supervisor to discuss my transfer document. In view of this and the comments from the reviewers I have decided that after Christmas I will re write my transfer report to reflect these comments

21.12.10 Supervision with supervisor to discuss the way forward with my data analysis

Appendix 17: Research protocol

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days).

4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking consent	1	0	20 mins max	Hilary Cowan, principal researcher These will take place in the mother's own home at a mutually agreed time
Questionnaires	2	0	20 minutes per questionnaire	Mother will complete this in her own home independently
Interview	1	0	1 hour	Hilary Cowan, principal researcher These will take place in the mother's own home at a mutually agreed time
Video observation of mother child interaction	1	0	40 minutes	Hilary Cowan, principal researcher These will take place in the nearest Child Development Centre to the family home

Total time = 190 minutes