How do parents of children with autism who have received intensive child psychotherapy view the treatment now

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A thesis submitted in partial fulfilment of the requirements of the University of East London in collaboration with the Tavistock and Portman NHS Foundation Trust for the Professional Doctorate in Child Psychoanalytic Psychotherapy.

June 2020

Word count: 53,092

Supervisors: Louise Allnutt and Nancy Sheppard

Abstract

This retrospective study focussed on the parents of children with autism, aiming to understand more about the meaning they made of their experience of intensive child psychotherapy. Historically within the field, psychodynamic treatment has been viewed as judgemental. There is currently debate, both inside and outside the profession, about the aims and value of child psychotherapy for such children. A literature review revealed limited research on parents' views of intensive psychotherapy for children with autism.

Three mothers participated in semi-structured interviews. The resulting data was analysed using Interpretative Phenomenological Analysis which allowed for an in-depth exploration of the complexity of parents' relationships with the intervention. Three themes emerged: the first highlighted the experience and impact of loss; the second showed differing relationships with feelings and the self; the third illuminated relationships with help and change.

The study found that parents of children with autism can experience a powerful sense of loss and may begin therapeutic work in the midst of a trauma. The findings suggested that parents' relationship with intensive child psychotherapy is likely to be complex. Parents communicated that the help they and their child received led to an improved quality of life.

The study highlights a need to pay attention to parents' vulnerabilities when they initially engage and to stay connected to the impact of loss throughout the intervention. Recommendations include a consideration of the needs of the parent as well as the child through careful assessment. There is support for flexible models of treatment. The findings suggest the appropriate nature of child psychotherapy as part of a multiagency package of support for families of children with autism and point to a need to raise the profile of the intervention amongst other parents, within the discipline and across the wider provision.

Declaration

I hereby declare that the contents of this thesis are entirely my own work; other sources of information have been cited throughout. Any work, published or unpublished which I have quoted, or to which I have referred, are referenced in the body of the thesis and cited in full in the reference list. This project has received ethics clearance from UEL and permission to conduct the study has also been given from the Local Authority in which this study took place.

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Abbreviations

CAMHS: Child and Adolescent Mental Health Service
IPA: Interpretative Phenomenological Analysis
ASD: Autistic Spectrum Disorder
DSM-5: Diagnostic and Statistical Manual of Mental Disorders
NAS: National Autistic Society
NICE: National Institute for Health and Care Excellence
NHS: National Health Service
PhD: Doctor of Philosophy
MER: My Emotional Response
IRAS: Integrated Research Application System
REC: Regional Ethics Committee
HRA: Health Research Authority
PIS: Participant Information Sheet
UEL: University of East London
SLDOM: Sheffield Learning Disabilities Outcome Measure
ACP: Association of Child Psychotherapists

Acknowledgements

I would like to thank the parents who agreed to take part in this research for their generosity.

I am grateful to both my research supervisors, Louise Allnutt and Nancy Sheppard, for their encouragement, challenge, patience and enthusiasm throughout the study.

I would also like to thank Magnus Bastian and Graham Hayday for their attentive proof reading and my husband and parents for their incredible support.

Chapter 1 Introduction

In this introductory chapter I will address my motivation for the study by describing significant experiences in my professional background which led me to want to enquire further into this topic. I will set out the aims for the research and describe the thesis structure with a brief summary of each chapter.

1.1 Professional background

Before training as a child psychotherapist, I worked for 14 years as a music therapist with children on the autistic spectrum in a special school. The children were typically severely affected with no language. The school was outstanding, believing in an holistic approach to children's education and finding many ways to support parents. In this context, I was able to develop family music therapy groups which included a reflective space for the parents alone. Three parent/child dyads attended weekly for at least a year. In the music sessions, I witnessed and tried to support the relationship between parent and child, observing the struggle of what Rhode (2007a) has described as the circle of discouragement. The parents' use of the talking session brought the ongoing experience of parenting children who were so remote further into focus for me.

In the same school, I began to see a child weekly for music therapy whom I will call Freya. Freya had a traumatic background and was at that time living with her father and had no contact with her mother. She was non-verbal and had a reputation in the school for being wildly out of control and impossible to manage in the classroom. Alongside our music therapy sessions, Freya also began intensive child psychotherapy in a clinic setting.

I worked with Freya for seven years. Initially, she would not come near me or the piano and removed my hands if I attempted to play. However, she was drawn to the music and she began to take risks interacting with me so that slowly, over many months, we were able to find each other. Freya loved to create melodies on the piano. She gradually allowed me to accompany her, responding to my melodic and harmonic suggestions in her playing. Our improvisations developed shape, with clear endings. We often recorded our music and sat together after playing, listening intently to what had been possible in our communication.

At school reviews, Freya's therapist from the clinic and the supervisor for the case, who was Anne Alvarez, spoke about the psychotherapy work with Freya and her father. Hearing the psychotherapists' thinking about Freya's difficulties, and then observing her slow recovery had a profound effect on me. She became a different child, one who was verbal, calm and able to learn. I recognised in this experience the first stirrings of desire to train as a child psychotherapist myself.

During my second year of clinical training, attendance at the Tavistock Autism Workshop clarified for me that I have a special interest in this field. As part of my training, I was able to work with a boy with autism for two years. I wrote about the case for my special interest paper and through it became more aware of the crucial role of the parent work.

The case was part of my clinical work for a community CAMHS service. Initially, my placement supervisor had hoped the case would be an intensive piece of work. However, the multidisciplinary team were not happy with this use of resources and reluctantly allowed me to offer once weekly sessions. In general, children with autism and their families were not seen as part of CAMHS except for diagnostic reasons.

These experiences left me with questions about what child psychotherapy has to offer children with autism. I was particularly interested in the views and experiences of parents. When the time came for me to explore possible subjects for research, I was keen to use the opportunity to understand more. I will describe how the research evolved from this point in the research methods chapter.

1.2 Research aims

This retrospective study aims to investigate the views of parents whose children with autism have received intensive child psychotherapy. I hoped to explore whether the parents considered the therapeutic intervention to have benefitted their child and/or themselves. I wished to understand something of the complexity of the parents' relationship with the therapy and the factors affecting it.

Following on from Cathy Urwin's work (2011) I was keen for parents' opinions and experiences to be the focus of the research. I had seen how parents' views are very powerful in influencing other parents' decisions about suitable treatment of their children. I hoped through this study to give parents a voice in what has historically been considered a judgemental treatment for children on the autistic spectrum.

1.3 Thesis structure

Following on from this introductory chapter, **chapter 2, literature review** is an attempt to provide context for the research question. I will discuss the literature related to four main areas of inquiry: defining autism; clinical work in the field; parents' experiences of autism; and parents' place within child psychotherapy treatment. I will conclude by describing gaps in the literature as well as the significant themes which emerged from the reading. I will draw on the literature review in the discussion chapter, placing the study findings in context.

In **chapter 3, research methods** I will describe how the research question evolved, outline the decisions made about the method of research, Interpretative Phenomenological Analysis (IPA), and discuss why the method is appropriate to answer the research question. I will consider IPA's philosophical framework as well as the relationship between IPA and psychoanalytic thinking. I will then describe in detail how the research method was applied and the data collected. The chapter will end with a description of each stage of the analysis of the data and decisions about study redesign.

I have included a separate **ethics chapter (chapter 4)** in order to address the formal ethics process, the ethical dilemmas inherent in the research design and those which arose during the research process. Consideration is given to managing patient distress in research as well as writings on working sensitively and ethically with defended participants.

In **chapter 5, research findings** I present the findings of the IPA analysis. I describe three main themes:

- Experience and impact of loss
- Relationship with feelings and the self
- Relationship with help and change

I explain the sub-ordinate themes which sit under each super-ordinate theme. I then present each family in turn, evidencing the significance of the themes for each case.

Long quotes from the participants' transcripts are included for transparency and to illustrate nuance. I conclude the chapter with a table showing the relationship between themes and across families.

The findings of the research are placed in context and validated in the **discussion** in **chapter 6**. I discuss links between themes and consider how the findings relate to the existing literature. I use additional methods of triangulation to provide validation, such as referring back to my reflective journal and to an interview with a child psychotherapist experienced in the field which was conducted before the parent interviews took place. In this way I provide robust confirmation of the method and themes.

Chapter 7, **summary, evaluation, recommendations and conclusions**, will summarise the key findings from the research and outline implications for improving practice within the child psychotherapy discipline and across general provision for families. I will evaluate the study and consider ideas for future research to build on knowledge in the field. I will conclude with some final reflections on the research experience and what has been learnt.

Chapter 2 Literature review

Introduction

The following literature review provides context for the research question. I will focus on four main areas of inquiry which emerged through reading as relevant to the study.

- **What is Autism?** An outline of historical views, developments in theory and the current context in the UK.
- **A clinical perspective.** Child psychotherapy with children with autism: the suitability of the treatment; technical developments; aims of treatment; clinical decision making; assessment of changes and intensive treatment.
- **Parents and autism.** The internal experience of having a child with a learning disability. The particular nature of autistic symptoms and impact on parental capacity.
- **Parents and child psychotherapy.** Parental engagement and preparatory work, parents' hopes and expectations for the work and aims of concurrent parent work.

I will begin by explaining my strategy for the literature review including decisions taken about what to include. I will then discuss each of the key areas above in turn. The conclusion will highlight significant themes from the literature which I will refer back to in the discussion section of this thesis. I will identify gaps in the literature and describe the need for further research into parents' views of child psychotherapy with their children with autism.

Strategy for literature review

I began this review by revisiting key texts I was familiar with from the Tavistock Autism Workshop which are listed below.

- Alvarez (1992) *Live Company: Psychoanalytic Psychotherapy with Autistic, Borderline, Deprived and Abused children*
- Alvarez and Reid (1999) *Autism and Personality. Findings from the Tavistock Autism Workshop*
- Rhode and Klauber (2004) *The Many Faces of Asperger's Syndrome*
- Simpson and Miller (2004) *Unexpected Gains: Psychotherapy With People With Learning Disabilities*
- Rhode (2008) *Joining the Human Family*
- Urwin (2011) *Emotional Life of Autistic Spectrum Children: What Do We Want from Child Psychotherapy Treatment?*

I then searched for more recent writings by these authors and used the bibliographies from their papers to identify wider reading. Following this, I used the Tavistock and Portman library database and Google Scholar to identify texts which were closely related to my key areas of inquiry by searching for words such as “autism”, “parents” and “intensive child psychotherapy”. I followed suggestions for appropriate literature from my supervisors. I imported the references into Endnote to keep track of my reading.

Two recent, significant reviews emerged as particularly helpful:

- Rhode (2018) *Object relations approaches to autism* - focussing on work from within the British Object Relations tradition.
- Singletary (2015) *An integrative model of autism spectrum disorder: ASD as a neurobiological disorder of experienced environmental deprivation, early life stress and allostatic overload.* This American theorist provided an extensive review of research across neurobiology and psychoanalysis.

The texts listed above are central to this literature review and will be discussed under each area of inquiry alongside other relevant writings.

In my original proposal for this research, I planned to consider literature related to children’s and therapists’ views of child psychotherapy. As my research evolved, I re-focussed on the question (this process is discussed in depth in chapter 3 research methods) and recognised that parental experience was at the centre of my research. Children's and therapists' views of therapy, whilst interesting, were less relevant to my question. I focussed instead on parents' experiences of having a child with autism and included some literature from the field of disability in general.

I will now discuss the literature related to each of the key areas of inquiry.

2.1 What is autism?

Current views on the nature of autism could be described as being as diverse as the condition itself (Spectrum, 2019). In the field of child mental health and within individual CAMHS teams, it would not be surprising to find a range of perspectives amongst clinicians. Medical and social models of autism (Waltz 2013; Woods 2017) might sit alongside views on the value of neurodiversity, with implications and interpretations of what might or might not constitute an appropriate intervention for the diagnosed child and their family.

It is beyond the scope of this thesis to explore all contemporary views of autism. In order to focus in and provide relevant context for the research question, this section of the literature review will consider describing and defining autism from the following perspectives:

- Key historical developments in describing and defining autism as a disorder including the controversial writings of some psychoanalytic thinkers regarding the aetiology of autism
- Understanding autism including developments in psychoanalytic theory and concluding with contemporary views on aetiology
- The current criteria for diagnosis and prevalence of autism in children in the UK

2.1.1 Describing and defining autism as a disorder

Leo Kanner (1943) was the first to describe "early infantile autism" in his paper *Autistic Disturbances of Affective Contact*. The following year, without knowledge of Kanner's work, Hans Asperger published his thesis *Autistic Psychopathy in Childhood* (translated into English by Wing, 1981). Since these first uses of the word, “autism” has been used to describe a large variety of symptoms (Alvarez and Reid, 1999).

In 1967, Bettelheim’s work highlighted people who had a crucial problem with a sense of identity, a lack of a proper personhood (Rhode, 2018). Wing and Gould’s (1979) huge study of 35,000 children confirmed Kanner’s original idea about three symptoms of autism: severe social impairment; severe communication difficulties; and the absence of imaginative pursuits, substituting them with repetitive behaviour (Alvarez and Reid, 1999). The attempt to describe autism and grapple with where the deficit really lies continued.

In 1985, Baron-Cohen *et al*. developed the “Sally-Anne Test”, a psychological test using puppets designed to assess an ability to know whether others can have beliefs that are different from one’s own. They described a cognitive deficit, those who lack the capacity to form an adequate “theory of mind” (Premack and Woodruff, 1978). Frith (1989) and Frith and Happé (1994) went on to describe a further cognitive deficit concerned with general information processing which they called “weak central coherence”; a difficulty arriving at an overall impression from a collection of details.

Historical controversies

At the early stages of psychological work with children with autism, some psychodynamic writers became interested in investigating the cause behind the condition and took rather extreme positions. Two camps developed: the cognitivists, believing in a genetic or other organic cause, and those who considered the environment was the cause of the condition. An idea evolved that psychoanalysts believe parents are to blame for autism. Kanner (1943) wrote about the parents he met, describing them as highly intelligent and emotionally cold. Bettelheim (1967) went on to discuss parents having a highly damaging effect on their children with autism (Rhode, 2004). Such writers, who placed an enormous burden of blame particularly on mothers, caused damage to the reputation of the work in this field which had far reaching consequences. The psychoanalytic community in general was paralysed for decades. Those who considered that relationships were significant could easily be dismissed as aligning with Bettelheim. In this climate, psychoanalytic writers had to proceed with extreme caution.

2.1.2 Theoretical developments

Psychoanalytic work with children with autism has deep roots. Klein described her treatment of a now recognisably autistic boy, Dick, in her 1930 paper, *The Importance of Symbol Formation in the Development of the Ego.* As work with these children continued and focus turned to the meaning of the symptoms rather than the causes of autism, important theories emerged.

Failures in the process of separation

Mahler (1961) believed all children began life in a state of fusion with their mother and that the process of becoming an individual occurred over a series of stages. She saw failure in the process in those with autism. This idea underpinned Tustin's (1972) theory of an early developmental stage of "normal primary autism". Tustin changed her mind about this following new child development research, understanding later in her career that human babies were born ready to relate (Tustin 1990, 1994).

Tustin described how separation is felt to be an unbearable trauma for those with this disorder. Her patient John (1986) led Tustin to understand that John experienced the nipple as an actual part of his mouth. Without it, he felt part of his mouth had been torn away. "The implication was that separation and separateness are a tragic, unbearably painful wound when two are ripped apart" (Klauber, 2001 p169). Tustin (1986) described these children's "traumatic awareness of bodily separateness from the mother … before their psychic apparatus was ready to take the strain" (p23). She spoke about existential anxieties, the fear of being gone, and about "having lost an essential bodily bit felt to be necessary to ensure survival" (Rhode, 2005 p57). Without individuation, the autistic child fails to develop a sense of self.

Autistic defences

Clinicians thought about the defences used against these terrifying anxieties. Bettelheim (1967) was in touch with the life-and-death nature of the fears that led to the use of rituals. Mahler described the self-protective impenetrability she saw as "autistic armour" (1968). Tustin (1986) developed concepts of autistic objects and shapes. These were defensive sensation manoeuvres designed to keep such anxieties at bay. The hard "autistic sensation object", perhaps an actual object such as a hard toy, or part of the child's body, and the "autistic sensation shapes", soft bodily sensations experienced on the surface of the body, were used to keep meaning out. She considered how reliance on these sensations stopped shared perceptions developing and therefore impaired cognitive development (Barrows, 2004).

In her 2018 review, Rhode pointed out the central importance of Bick’s (1968) work on adhesive identification. Although these ideas did not develop from work with autistic patients, they provide a way of understanding “the catastrophic bodily anxieties and the deficits in symbolic thinking” that have been the focus of work in the field since Klein (Rhode, 2018 p708).

Bick described a space inside the baby where a sense of self could develop through identifying with a space inside the mother, if the baby felt its communications were accepted there. If this was not the baby’s experience, Bick considered how he might try desperately to avoid falling apart by relying on his own capacities, holding himself together using a “second skin”, which could for example be muscular or verbal. She described the baby avoiding terror through an adhesive mechanism, where he may cling to the surface characteristics of the carer. Rhode (2018) suggested this model correlates to Bion’s theory of containment.

The nature of the deficit

Melzer’s *Explorations in Autism* (1975) described children who were hypersensitive to other people’s minds, passionate, possessive and sensuous with very little sadism. He saw an interaction between these characteristics and depression in the mother during the baby’s first year which caused problems with containment (Rhode, 2018).

Alvarez, in her 1992 book, *Live Company*, challenged Baron-Cohen’s *et al.*’s (1985) idea of a problem with a theory of mind which they saw as a cognitive deficit. She felt that these ideas were based upon a barren idea of what the mind constitutes and relied upon a “one-person psychology”, “where deficit is purely a characteristic of the child” (Rhode, 2018 p711). Considering the “Sally-Anne Test”, Alvarez (1992) argued that psychoanalytic observers would be interested in the child’s inability to identify with the doll Sally. She explained that such a capacity is both cognitive and emotional, but involves “very particular processes which cannot even begin to be examined in a one-person psychology” (p194).

Hobson (1993) and Trevarthan *et al.* (1996) also considered the deficit as an earlier one of intersubjectivity; as Alvarez (2005) put it, “an impairment of the normal sense of mutual, emotionally based curiosity about, and desire for, interpersonal relationships" (p2). Alvarez (1992) described this model as a "two-person psychology", which acknowledges that babies are born with an innate desire to respond and interact with another person. Tustin (1990) linked this inability to empathise with an underdeveloped sense of self and saw how "putting themselves in someone else's shoes might feel like losing any sense of their own identity" (Rhode, 2008 p163-4).

Alvarez explained how problems with the original and fundamental, interpersonal desire to relate then result in cognitive deficits. Rhode (2004) described the link to Bion's idea that "cognitive processes develop out of emotional relationships" (p10). The desire to interact and respond to another is now known to be essential for the development of the human mind, a mind that Stern (1985) recognised as a place "where thoughts may occur, experiences be remembered, links made and imaginative life develop" (Alvarez and Reid, 1999 p2).

Tustin (1981, 1990) and Meltzer *et al.* (1975) recognized how the original autistic withdrawal produces what Alvarez suggested should be called a "progressive deficit" (1992, p190) as the child is repeatedly unable to take in new experiences during states of mindlessness. She described "the awesome power of an effect to become a cause of itself" (p187), explaining how the consequences of a feedback system can impact on the infant-mother relationship. Each partner "may become more and more insensitive to the other's ever more minimal cues, with grave implications for the baby's emotional development, and, I suggest, for his intelligence" (p187).

Alvarez (2005) used the terms primary and secondary autism, where primary autism is the original or very early deficit, and the secondary autism is the symptoms and behaviours the child develops to cope with the primary deficit. This followed on from Sinason (1986) who, writing about mental handicap generally, described an idea of a "secondary handicap". She explained how children born with a deficit develop a secondary disability resulting from "attacks on skills and intelligence as a way of coping with the handicap" (Simpson and Miller, 2004 pxxi).

Singletary (2015) stressed the infant's experience of deprivation even though growth-promoting input is available from the parents. "What originates in the child as an attempt at an adaptive response to a perceived (not actual) threat is truly maladaptive. Because of fear, the child shuts out what he needs the most, loving and helpful human interactions” (p94). Singletary considered that the child’s experience of being deprived is felt as a threat and results in psychological (toxic stress) and biological consequences (allostatic overload). His model of ASD aimed to explain the progression to and the ongoing symptoms of the condition.

Towards an integrated model

Alvarez (1992) explained her idea of the complexity of the aetiology. She described “a double helix where heredity and environment twist around each other in interacting spirals” (p187). Alvarez considered that following this, cognitive impairment in the child could be, “out of all proportion to the original weak heredity or original inadequate environment or even to both” (*ibid*.). She recognised a pull towards simplistic explanations for the condition. “Something so terribly inhuman in a human child seems as if it must have an equally terrible and powerful single aetiology” (p187-8).

In *Live Company*, Alvarez highlighted the considerable and growing body of evidence demonstrating brain abnormalities in autistic individuals (Dawson and Lewy 1989; Frith 1989; Gillberg 1990). She described “An interactional feedback model applied to the first days and weeks of life - where both nature and nurture are given their proper due” (Alvarez, 1992 p187).

In his 2015 review, Singletary stressed the need for a unifying and cohesive model of ASD and attempted to bring together research from across neurobiology and psychoanalysis. Rhode (2018) also described active research across genetics and biochemical, behavioural, developmental and psychoanalytic fields. She outlined recent work identifying 200 implicated genes and drew attention to possible differences in brain development and structure such as the seemingly atypical neural pruning seen in the second year of life in children with autism (Rutter 2001; Volkma *et al.* (2008); Singletary 2015).

Rhode (2018) noted that Rutter stressed the importance of environmental factors to the expression of genetic predispositions. Rhode described a central genetic endowment which interacts with the social environment, referring to Singletary’s (2015) description of biological predispositions interacting with hormonal factors, epigenetic influences, stress, and the nature of the small child’s relationships in bringing about behaviour to justify an ASD diagnosis.

Urwin (2011), when considering how definitions and theories of aetiology within the field have expanded to include genetic, neuroscientific, physiological, and psychodynamic, concluded that, “assuming one scientific, clinical or populist position holds the monopoly on truth about causation or appropriate intervention is misplaced” (p245), failing to reflect the reality of day-to-day life for children and their families.

2.1.3 Current diagnostic criteria and prevalence in the UK

The highly influential US manual *DSM-5* (2013) defines autism spectrum disorder using a dyad (rather than the previous triad) of impairments

- persistent difficulties with social communication and social interaction (which are now viewed as inseparable).
- restricted and repetitive patterns of behaviours, activities or interests (including sensory behaviour) present since early childhood, to the extent that these limit and impair everyday functioning.

Current prevalence rates in the child population of the UK of 1% are based on a 2009 study by Baird and colleagues of children aged 9-10 in the South Thames region. The authors stated this estimate should be considered a minimum figure (Baird *et al*. 2006).

The autistic disorder is widely described as a spectrum. The NAS (2016) explain that autistic people share certain difficulties, but being autistic will affect them in different ways. Urwin (2011) highlighted the increase in diagnosed children with very varying presentations. She described how such variations exceed what can be attributed to differences in IQ or the presence of co-morbid psychiatric disorders (Newschaffer *et al.,* 2007). In 2018, Rhode described how in her view, it may be more accurate to consider “autisms” rather than “autism”.

2.2 A clinical perspective

I will now outline how psychoanalytic treatment with children with autism has evolved and discuss the relevant literature for the following areas:

- Aetiology and treatment – is psychotherapy an appropriate treatment for children with autism? Developments in clinical technique
- Who might benefit - subgroups and clinical decision making

- The aims of child psychotherapy with children with autism
- The assessment of changes in children with autism receiving child psychotherapy
- Intensive Psychotherapy for children with autism

2.2.1 Aetiology and treatment

The historical controversy around the aetiology of autism had implications for treatment. For those who believed that autism was caused by an organic brain defect, it could be seen as a fixed and untreatable condition. There was often an accompanied understanding that psychotherapy, with its emphasis on emotional experiences, “cannot be relevant or useful, and indeed will do harm by arousing false hope in the parents” (Rhode, 2004b p5). Historically, when psychotherapy was seen to be successful with children with autism, this could be taken as providing solid proof against an organic aetiology of the condition (refuted by Alvarez in 1992) or as evidence of a mistake in the original diagnosis (Shapiro, 2000).

In 2005, Houzel and Rhode argued for psychotherapy as an appropriate treatment option, regardless of views on aetiology, pointing out that “even a purely organic defect would not be an argument against a psychological approach” (pxvi). As Alvarez, referring to Spensley (1985) and Sinason’s (1986) work, had argued in 1992, neurologically damaged patients could be helped both emotionally and cognitively by psychoanalytic therapy (p184).

In her 2011 paper, Urwin considered views on psychotherapy with children with ASD from within the psychoanalytic community. She noted how such children are defined by their difficulties within the areas that psychoanalytic psychotherapy depends upon – social interaction, communication and flexible thought and imagination (Wing and Gould, 1979) which could rule out psychotherapy as a treatment option. Difficulties with language and empathy could also be considered “serious obstacles” to analytic work by some psychoanalysts who were also researchers (Shapiro 2000; Van Schalkwyk and Volkmar 2015).

In 2018, Rhode considered that views about the value of psychodynamic treatment for children with autism were beginning to change due to successful early interventions by psychologists and psychiatrists (Wan *et al.* 2013; Green *et al.* 2017), a number of which showed an influence in brain function. (Dawson 2008; Ventola *et* *al.* 2014). In 2004, Rhode had described how new techniques of brain imaging were making it possible to see a link between emotional experiences and brain chemistry. In her 2018 review, she cited growing evidence to support the idea that a young child's relationships affect the structure of his brain and how it functions (Schore 1994, 2014; Perry *et al.* 1995). "What can happen … is that high-order pathways can be laid down which make it possible to manage experiences that would previously have been overwhelming" (Rhode and Klauber, 2004 p7). This is an argument against seeing a brain defect as unmodifiable and supports Symington's belief that "neurological growth can be stimulated and is not static. What remains static are people's expectations that change can occur" (1981, p199). Alvarez (2005) stated that "for all its apparent stasis, the autistic condition is much less static and more mutable than it sometimes appears" (p4).

Singletary's (2015) extensive review of research stressed the neuroplasticity of the brain and described ASD as a potentially reversible neurodevelopmental disorder. Rhode (2018) explained that many clinicians remain unaware of these developments in research. She acknowledged that the picture is complicated by a current lack of clear biological markers and the consequent reliance on behaviours to inform diagnosis.

Technical developments

The profound difficulty in the ability to relate brought about developments in technique within child psychotherapy. In 1992, Alvarez considered how a modified object-relations theory, "with an understanding of primitive or minimal objects, or pre-objects, and with distinctions between preconceptions and concepts" (p199), allows for the possibility of the theory to be applied to work with children "who seem by definition so clearly un-object-related" (p196).

Alvarez wrote about "a developmental view of defence" (1992, p114), highlighting the difficulties of a more traditional approach, "when analysts and therapists urge patients to face their fears, their yearning, their sadness, long before they have the resources and imagination to do so, they may be asking too much" (*ibid*.). Hobson (2011) explained the dangers in assuming more ability to understand than is evident and Urwin (2011) pointed out the potential then for missed opportunities to foster capacities that are emerging and necessary for growth. Rhode (2018) illustrated this idea by referring to a number of patients with autistic spectrum condition

(Williams 1992; Gerland 1996) who have “described their bewilderment at interpretations concerning family relationships” (p714). Rhode explained that clinicians who work within an object relations framework focus on a far more primitive level, one of bodily and sensory experience.

Alvarez (1992) described the importance of using interpretations in a way that would allow the child to take them less as concrete fact. When discussing transference interpretations, Rhode (2018) described the complicating factor of different aspects of the child’s personality which co-exist, with the non-autistic aspect being “capable of more familiar transference manifestations” (p715). She referred to a paper by Ahumada and Busch de Ahumada (2017) that claimed interpretation (particularly transference interpretation) may be felt to be intrusive and should be avoided with these children, focusing instead on “the quality of the therapist attention” (Rhode, 2018 p715).

In 1992, Alvarez explained the importance of differentiating, of recognising when obsessional mechanisms are being used in a defensive way and when they might suggest a more developmental attempt “to achieve some slight order in the universe” (1992, p113). She described a “reclaiming” of the undrawn child back into the world of human feeling, relating this to the normal interaction between mothers and babies. This more active technique was different from what she felt was required for a withdrawn, shell-type child.

> Where the idea is too far away, it may need amplifying, where it is too close for perspective, binocular vision and alpha function to operate, it may need containing and distancing. Such a patient is in no doubt of his being alive; his problem is that he feels overwhelmed by terror of death (*ibid*., p89).

In general there was an increased focus on working with the “non-autistic” part of the personality (Urwin, 2011). “Here the challenge is to discover ways to tap into the children’s potential to be, and to want to be, engaged with someone else” (Hobson, 2011 p241). Alvarez (1999) proposed using simplified language and non-verbal communication, looking out for precursors of social/cognitive development. Alvarez and Reid (1999) said, “the therapist must have a mind for two, energy for two, hope for two, imagination for two” (p7). Tustin (1981) described this idea beautifully, “the therapist demonstrates by words and actions … I will lend you my “thinkings” so that you can develop “thinkings” of your own” (p199).

2.2.2 Clinical decision making

There are of course limited resources available within the NHS and so difficult decisions have to be made in teams about which children could most benefit from psychotherapy (Barrows, 2004). A number of psychotherapists have described subgroups of children with autism and considered those who might be most suitable for this kind of intervention.

Tustin (1972) saw a difference between an encapsulated shell-type child and a more passive amoeboid type. Wing and Attwood (1987) used classifications of aloof, passive and active types. Alvarez and Reid (1999) distinguished further, considering the differences between "undrawn" and "withdrawn" passive children, and between "thick-skinned" and "thin-skinned, hypersensitive" aloof types of patients. They recognised that children do not stay conveniently in diagnostic categories, and that "the autistic state of mind fluctuates from moment to moment within any individual with autism" (*ibid*., p9).

Reid (1999b) proposed a new subgroup of autistic post-traumatic developmental disorder which cut across Wing's subgroupings. In addition to the autistic child's traumatic experience of separation outlined above, Reid considered the effect of an actual external trauma on the child and family. She drew attention to the similarity of the symptoms found in a subgroup of children with autism and those seen in children without the condition who have post-traumatic stress disorder. "I am hypothesising that an experience of trauma in the first two years of life may be a precipitating factor in the development of autism in this sub-group" (*ibid*., p93). Reid suggested this may combine with a biological or genetic predisposition in the infant and pointed out that many children who suffer apparently similar traumas do not develop autism, and some children with autism may be more severely affected as a result of the trauma. Reid went on to distinguish between kinds of trauma and how they might be experienced, describing a difference between the effect of actual external trauma on an ordinary sensitive very young infant and the apparently traumatising effect of ordinary life experiences on a particularly hypersensitive infant.

Rhode (2018) drew attention to Rutter's 1999 study of Romanian orphans adopted in the UK. A small percentage of the children developed behaviours typically seen in autism presentations following a massive trauma. There were however some differences between these children and those with "naturally occurring" autism.

Rutter's group contained equal numbers of boys and girls (unlike in naturally occurring autism where current estimates suggest three times as many boys are diagnosed than girls (NAS, 2019)) and they also showed improvements between the age of four and six. Brown *et al*.'s study in 1997 showed that, in a sample of congenitally blind children, half met the criteria for autism, and autistic features were prevalent in those remaining. Again, these children who met the criteria for diagnosis improved over time, unlike children with autism who are not blind.

Urwin (2011) described how some children with autism "show extreme sensitivity or hypersensitivity to others' emotional states", referencing Meltzer *et al*. (1975), Tustin (1981) and Urwin (2002). She considered how many children with ASD, "if not all to some degree, respond well to 'being understood' or to having confusing states of mind comprehended and responded to appropriately" (p246). Urwin considered that this kind of sensitivity might be an indication for psychotherapy, as is the case with children without autistic symptoms (Rustin, 2000).

Rhode (2018) described an idea of "optimal responders". She outlined studies of intensive interventions with very young children with ASD, such as Dawson 2008; Dawson *et al.* 2012; Ventola *et al.* 2015 and Fein *et al.* 2013 where some children with an ASD diagnosis "have come to be indistinguishable from a control group" (p704). Rhode compared Ozonoff's 2013 paper in which she suggested that science supports the hope of recovery from ASD, with the more pervasive view among clinicians and parents of autism as a concrete thing "that children either 'had' or did not 'have', in contrast to the psychoanalytic view that autistic behaviours are an attempt to deal with catastrophic anxiety or deficits arising out of the interaction between the environment and the children's innate endowment" (Rhode, 2018 p704). Rhode agreed with Reid's (1999a) view that not all children on the spectrum are responsive and that an extended family assessment is indicated.

2.2.3 Aims of treatment

As well as considering which kinds of patients with ASD might be most receptive to psychotherapy, there has been a need to clarify the aims of the intervention. In 1999, Alvarez and Reid expressed their hope for treatment with such patients, that "Like plants which need a 'heeling in', they may begin to put down roots and to grow mind" (p6). For the clinician working with the child and family, Reyes-Simpson (2004) described a need to find a balance, to hold on to hope and remain realistic, "we have to face the limits of what we can achieve and the limitations of our patients' potential; however, at the same time we hold on to the hope that our patients will develop" (p124).

In 2011, Urwin's central paper, *Emotional Life of Autistic Spectrum Children: What We Want from Child Psychotherapy Treatment* explored the aims of child psychotherapy with children with ASD. She explained that "the key consideration is the degree to which the child might benefit" (p248). Urwin defined this benefit as "having meaningful experience, and/or that it promotes developmental change or leads to a positive impact on the family and the child's capacity for learning and engagement" (*ibid*.).

Urwin's HETA (hopes and expectations for a treatment approach) model developed aims for treatment relevant to the particular child. I will consider the clinicians' views about treatment aims in this section and refer to parents' hopes and expectations in section 2.4, when discussing parents' views of psychotherapy.

In Urwin's research (2011), seven clinicians were asked to share their hopes for the treatment of their particular case after they had completed the assessment process and before the work itself began. Treatment aims included increased understanding of the particular child's anxieties and difficulties; greater organisation, flexibility and fluency; managing separations and change with increased confidence; and an improvement in curiosity and engagement. Urwin noted that this kind of improvement would help learning and help the child to benefit from other kinds of interventions.

Urwin (2011) stated that the hope that was most frequently expressed and referred to in all of the cases was for the treatment to bring developments in containment and regulation leading to the capacity to reflect on and name emotional states. She noted that they did not express hope that psychotherapy would help the children's capacity to understand other people's emotional states. There was hope for children to become less isolated and more emotionally available. Urwin recognised that "changes in emotional regulation and awareness are likely to have significant effects on family life" (p253).

Similarly, Singletary (2015) argued that treatment should aim to increase a sense of connection and decrease the experience of stress. He highlighted the importance of psychotherapy as an intervention in providing understanding of the child's inner world of experience. He explained how, “Making sense of the child’s experience of isolation and threat helps the ASD child feel understood and less afraid” (p81), which in his view makes recovery more likely.

A particular note on language development

Patten *et al.*, 2013, stated that approximately 25–50% of children with ASD do not develop functional verbal communication (Baghdadli *et al.* 2012; Lord *et al.* 2004; Sigman and McGovern, 2005), and it is rare for functional language to develop after the age of five (Pickett *et al.*, 2009). It is not uncommon for child psychotherapists to write about language development as an outcome of treatment, although it is perhaps unlikely to be stated as an aim. As Alvarez and Reid explained, “the therapist and patient embark together on a journey ... although neither can know quite where the journey will lead them” (1999 p4).

Rhode (2007a) summarised how, in typical development, “babies and their parents intuitively read each other’s cues, share each other’s feelings, and build up increasingly complex and sophisticated sequences of communication” (p193). During the second year of life, this leads to the development of speech. She considered how this process is derailed when babies are repeatedly unresponsive and their signals difficult to understand. It can be hard for parents to hold on to hope in their child’s capacities. Rhode highlighted the importance of parental expectations in early language development (e.g. Brazelton, Koslowski and Main 1974; Papousek 1992) and concluded that “any factors - physical or emotional - that undermine the parents’ confident expectations will be likely to have far-reaching effects” (p206).

In 1999, Rhode focussed particularly on children with ASD who speak using echolalia; when a child identifies with a voice in a superficial and unprocessed way, without meaning. She referred to writing by Donna Williams (1992) who described being echolalic. She explained that replying to somebody’s words would involve understanding the meaning of what had been said. “I was too happy losing myself to want to be dragged back by … understanding” (Williams 1992, p188). Rhode (1999) considered how “an anxiety about damage ... seemed to contribute to a difficulty in coming alive and in finding a voice of their own” (p80). Rhode recognised how progress in the therapist’s and child’s understanding of these anxieties led to a decrease in echolalia and increase in more meaningful ways of communicating.

In 2008, Rhode wrote about developmental imitation and introjections. She recognised that children with autism respond to being imitated, which has been at the centre of many diverse kinds of interventions. She noted, however, that “they do not themselves imitate in the natural, immediate way that other children do” (p153). Rhode described the difference between imitating in a relational way rather than mimicking or impersonating. She highlighted the importance of clinicians of being aware of this difference and recognising its significance developmentally. For Rhode, relational imitation implied a particular position in relation to the mother - like her, but not identical to her – which she saw as essential for introjection, “for experience to be taken in, built up and assimilated” (p154).

Urwin (2002) considered the place of the development of language in the child’s struggle to become a separate person. Writing of Bion’s (1962) work, Urwin explained how the development of thinking depends on thoughts finding a thinker. As thoughts become thinkable, so language develops. Here she saw the emphasis was on an increasing fullness of mental life. “Rather than language development distancing us from internal objects, it is part of the process through which we acquire them, and build an internal world” (p75).

Improvements in all of the above areas would have a significant impact on the family as a whole, helping children manage more socially and develop their capacity to communicate. Urwin (2011) summarised her thoughts on the aims of psychotherapy as hoping “to produce positive benefits for family life and the children's wellbeing” (p245).

2.2.4 Assessment of changes

I will now outline the main work in the area of outcome measures and studies with this population. There is a growing body of research into changes in autistic patients based on relational approaches. Within child psychotherapy, there are currently no controlled outcome studies. Rhode’s (2018) review points to a number of preliminary studies (Reid, Alvarez, and Lee 2001; Thurin *et al.* 2014; Rhode 2007)

Alvarez and Lee (2004) used video recordings during the treatment of a boy with severe autism that show an increase in dyadic, but not triadic interactions. Haag *et al.* (2005) looked at changes in children with autism under psychoanalytic treatment and proposed a grid of developmental capacities which allows for children to be psychoanalytically assessed as well as their progress to be tracked during treatment.

In 2007, Urwin proposed her HETA model in the paper *Revisiting 'What works for whom?: A qualitative framework for evaluating clinical effectiveness in child psychotherapy*. This paper is concerned with child psychotherapy treatment across all presentations and conditions. Urwin was responding to the urgent need for child psychotherapy to find a way to demonstrate clinical effectiveness. As she explained; "The challenge is to find ways of doing this that respect the psychoanalytic process and the complexity of our cases and working contexts" (Urwin, 2007a p134). Urwin discussed the many difficulties with the gold standard of research, the randomised controlled trial (RCT) for child psychotherapy treatment as an intervention. One such difficulty was the problem of isolating child psychotherapy treatment from the crucial support that will be occurring simultaneously. Richardson *et al.* (2003) described how children with autism and their families receive support across multiple agencies. Good liaison and communication in the network is necessary for any to be effective. The RCT is ill-equipped to capture this complexity.

Urwin (2007a) described the need to address the issue of whether treatments work from differing perspectives. She stressed the need to find constructive ways of involving parents, patients and referrer in evaluating outcomes. Her HETA model aimed "to make parents' experience of the child's progress in psychotherapy intrinsic to the evaluation process" (p136).

In her 2011 paper, Urwin stressed that, "Given the great variation between ASD children, evaluating success in psychotherapy treatment must be relative to the individual child" (p249). The seven participants in her study had, according to parents' and psychotherapists' ratings shown some or notable progress across all items, some being considerable, by the end of the second term of treatment which improved further for all except one child at the end of the year.

Rhode's 2018 review drew together studies which showed encouraging outcomes for this population, stressing the importance of early intervention, both in those that are not analytic (Chawarska, Klin and Volkmar 2008; Dawson 2008; Fein *et al.* 2013; Green *et al.* 2017) and those which are analytic (Houzel 1999; Lechevalier 2004; Laznik 2007; Rhode 2007a; Ahumada and Busch de Ahumada 2017; Acquarone and Jimenez Acquarone 2016).

2.2.5 Intensive psychotherapy

I will now consider writing on intensive psychotherapy for children with autism. I found little literature discussing the particular value of three-times-weekly sessions for this group of patients.

A number of writers have described the value of the psychoanalytic setting for children with ASD. In *Live Company*, Alvarez outlined how the reliability and regularity provided by the setting, along with the structure of the psychoanalytic technique, “provide an opportunity for structure and order to begin to develop in the child’s mind” (1992, p4). Alvarez saw her patient Robbie five times weekly at one stage in his treatment when she felt this was needed. She described “his breakdown, or rather break-out from his autism, which made everyone feel he was coming alive, and both needed and could use more intensive treatment” (1992, p84).

In 1999, Alvarez and Reid described how

> The regularity of the appointments, together with the consistency of the location of the sessions, is important for the recovery of all patients in psychoanalytic forms of treatment, but especially so for autistic patients where a safe, predictable setting is often the first thing which impinges on and attracts them (p6).

Rhode (2004) described the importance of the repeated exposure to the experience of being understood and how this leads to understanding oneself better, allows for the development of potential, and sometimes to the growth away from autism. In *The many faces of Asperger’s syndrome*, Rhode and Klauber expressed their view that intensive treatment seemed particularly helpful for this condition and spoke about a particular case which benefited from moving from once weekly to three times weekly sessions (2004, p 273).

Urwin (2011) discussed how an increase to two sessions weekly allowed for “a greater sense of consistency and structure” (p258). Attending a clinic three times every week for a year is a huge commitment. Urwin referred to this when she described how “the family must also be able to sustain the process through difficult times” (*ibid*., p248).

2.3 Parents and autism

In this section I will discuss writing from child psychotherapists on the experience of being a parent of a child with autism. As the literature is sparse, I will include relevant texts from psychoanalytic writing on learning disability. I will focus on the following areas

- The internal experience of parents who have a child with a learning disability including the contemporary controversy around disability and loss
- Child psychotherapy writing on the particular nature of autistic symptoms and the impact on the developing parent/child relationship.

2.3.1 Parents of children with disabilities

Internal impact

Some writers (Solnit and Stark 1961; De Groef 1999) have described a narcissistic "blow" experienced by parents when giving birth to a learning disabled child. They explained that, as a child is seen as an extension of oneself, there is damage to the parental ego when a child is born with disabilities. In 1979, Tischler recognised how a bad internal voice, common to all of us, is strengthened in parents when they have a child who is not developing typically. Rhode (2018) movingly noted that such parents live with a sense of being incapable of producing a flourishing child.

Disability and loss

In her 1983 paper, *The psychopathology of handicap*, Bicknell described how mothers who gave birth to a child with a disability experienced feelings of loss of the hoped for perfect child.

Watermeyer *et al.*'s (2014) paper, *Mothers of disabled children: in mourning or on the march?* addressed the contemporary controversy around disability being considered as a loss. The paper described a focus on feelings of loss within psychoanalysis versus researchers from the social model who are opposed to a view of child with a disability as requiring mourning, being concerned with equal rights for those with disabilities. Watermeyer *et al.* argued that the two positions do not need to be mutually exclusive and made a case for feelings of ambivalence in parenthood, stressing the need to allow space for the parents' actual experience and feelings.

2.3.2 The particular nature of autism

Some child psychotherapists have crucially written about parents' experience of autistic symptoms in their child, recognising the enormous impact such symptoms have on the developing parent-child relationship.

Impact on parental capacity

Alvarez and Reid (1999) described the deeply dehumanising experience of an autistic child showing interest only in parts of the parent for functions, "to have one's hand grasped without even a glance at one's face" (p8). They considered how a repeated dehumanising experience can wear away at spontaneity and ordinary human warmth. Rhode (2007a) stressed how an unresponsive baby giving confusing signals is "devastatingly undermining and invalidating for parents" (p193). She noted that when professionals are unresponsive to concerns, parents can often feel doubly invalidated.

Hatred and guilt

Klauber considered painful feelings of hatred. "What is often so hidden within the submission to the tyrannical demands, is guilt about hatred of the disability and of the child herself. How can one admit to sometimes feeling hatred for a disabled child who looks like an angel? How can one be firm in the face of the tragedy displayed on her face?" (1999, p42) Simpson and Miller (2004) considered the difficulty parents may have in bearing the reality of their child's disability due to their overwhelming feelings of guilt.

Isolation

Klauber (1998) wrote about the way in which families of children with ASD can become very isolated within their communities. Doig's (2012) study focussed on the particular experiences of Bangladeshi parents of diagnosed children. Many of her nine participants spoke about the challenges they faced as a result of poor understanding of autism within their culture.

Alvarez and Reid (1999) considered experiences of public humiliation, when a child looks ordinary but behaves oddly, describing the impact on the entire family. "Their lives may become severely limited, with consequent stress on the parents' marriage and effects on the mental health of everyone" (p3).

Trauma

In 1999, Reid explained her view that each family with a child with autism was to some degree suffering from post-traumatic stress. “For parents to feel that they are not really interesting to their children and that they have no real impact on them or influence upon their behaviour, is to feel real despair” (1999a, p17).

Klauber (1999) described the consequences of the trauma and loss that are a result of having and living with such a child (p34). As Reid put it, “no matter how life started out for each of these children and their families, by the time of referral it is usually the parents who are feeling traumatised, desperate and often with little hope and with a damaged sense of personal worth” (1999a, p17). Such writers saw similar symptoms of trauma and depression in parents of children with autism that Kanner (1943) and Bettelheim (1967) had described, but crucially recognised the consequence of parenting such a child. As Klauber (1999) pointed out, “it is easy … to confuse the effects of the child’s autism (on the child itself and the family) with its causes” (p34).

The circle of discouragement

Alvarez’s views on autism as a progressive deficit were underpinned by Stern and Trevarthan’s work on mother-infant attunement. Through analysis of videos, Stern (1977) showed how mothers and infants are extremely sensitive to each other’s cues. Trevarthen described the beautiful, unconscious musical dance between mother and child (Malloch and Trevarthen, 2009). When a child has autistic symptoms, he does not search for and elicit responses in his mother, who in turn becomes discouraged. The dance does not happen.

Rhode helpfully noted how, in face of repeated rejections and discouragement, exhaustion is experienced by parents and professionals alike. “Their hopefulness can be undermined, and they can become less able to respond to what are often minimal cues” (2007a, p202). She described how a circle of discouragement becomes established and stressed that in this context it becomes difficult for parents and professionals to notice, remember and believe in the child’s capacities (*ibid*.).

Graham Music, referring to Rutter’s study of Romanian orphans (1998), drew attention to the potential neurobiological element in this picture, as the study showed that the children with autistic like symptoms, did not release normal levels of oxytocin when they were cuddled by their adopted parents (Wismer Fries *et al*.,2005). He explained that this love hormone is usually present in both parent and child during loving contact. Music considered this significant in understanding psychotherapists' countertransference feelings of coldness and deadness which are described in work with autistic patients (Music, 2009).

2.4 Parents and child psychotherapy

Across the field of child and adolescent psychotherapy, work with parents is typically desired as an integral and often essential part of the intervention. The child psychotherapy perspective acknowledges that "everyone in the family system is affected by everyone else" (Rustin 2009, p215). In 2009, Rustin drew attention to the evidence base (Kennedy 2003; Trowell *et al.* 2007), concluding that "parallel work with parents is as important as we have always believed" (p207).

Writings on parent work within the discipline focus on its value and aims and the variety of forms it may take as well as the difficulty providing such work in current, under-resourced services (Tsiantis 1999; Rustin 1995, 2009).

To give appropriate context for the research question, this section of the literature review will focus on the parents of children with autism and writings on their place within and engagement with this intervention. I will discuss literature on:

- Parental engagement with intensive child psychotherapy including thoughts on preparatory work
- Parents' hopes and expectations of the intervention
- Aims of the parent sessions concurrent to the child's individual psychotherapy

2.4.1 Parental engagement and preparatory work

In 1999, Klauber wrote compassionately about the specific difficulties parents of children with autistic symptoms may have in engaging with professionals, noticing how seeking help could feel like "a mine field filled with the fear of judgement and criticism, compounded by the dreadful stirrings of the memory of noticing something was wrong" (p36).

Reid argued against the traditional assessment model for children with autism. As a primary aim of the therapy is to facilitate communication within the family, she felt it was unhelpful to assess the child in separate room, before establishing a connection with the parents. Reid saw danger in the therapist being seen as an “expert” and recognised how the gulf between parents and child could be widened, which may, “unwittingly increase parental helplessness and despair” (1999a, p19).

Reid (1999a) proposed a period of extended assessment before the beginning individual psychotherapy. She felt this would allow for some processing of the diagnosis as well as provide the clinicians with time to see how the family manages the child’s difficulties and how they respond to thoughts from the therapist about meaning. This suggested extended time frame also perhaps indicated how sensitive this work needed to be, with the ripples of Bettelheim’s (1967) damaging ideas still being felt. A longer assessment period would provide time to slowly approach the idea that relationships are important.

Urwin (2007a) described the family work, taking place before individual psychotherapy begins, which could include cross-discipline interventions. She stressed the importance of the feedback meeting as part of this work, connecting the reflections of the therapist with the parents’ own experiences and understanding of their child. “The connection parents make with a child psychotherapist at this time may be crucial in enabling them to sustain commitment to a lengthy and difficult treatment” (*ibid*., p136). In her 2011 paper, Urwin noted that there was a shift in the way parents expressed their concerns about their child after feedback from the assessment, revealing more fine tuned thinking or more compassion, supporting the view that the assessment has a role of an intervention in its own right (Reid, Alvarez and Lee, 2001).

Rhode (2018) has continued Houzel’s (1999) work on therapeutic infant observation. A therapeutic observer visits the family in their home giving sympathetic attention to parents and child. The work is offered to infants at risk of developing communication disorders and has shown good outcomes. Rhode described how it may be particularly valuable for families where the circle of discouragement has become entrenched. Rhode noted that through this work, parents “can begin to feel, if they did not already, that they and their child are worth paying attention to ... they begin to realise how precious is their own gift of attention” (Rhode 2007a, p198). This work with parents and child responds to the need for early intervention which is evidenced in studies from within and without the analytic community (Rhode, 2018).

2.4.2 Parental hopes and expectations

Urwin's 2011 paper discussed the hopes of seven sets of parents of children with ASD who were about to begin weekly psychotherapy for at least a year. She considered how the hopes expressed, in the areas listed below, reveal something of the powerful impact a child's difficulties have on family life.

- anxiety
- separations and transitions
- peer relationships, appearing avoiding or uninterested
- narrow fields of interest - hoping for more evidence of imagination
- understanding and managing their own emotions
- aloneness and hoping for the child to be happier

2.4.3 Aims of concurrent parent work

In line with thinking across child psychotherapy client groups, concurrent parent work for families with children with autism is considered an integral part of the treatment. For such parents it is perhaps particularly desirable. In 2011, Urwin described parent work as an invaluable aspect of the intervention for these children and their families.

As part of the intensive psychotherapy model, parents would typically be seen fortnightly by a second clinician. This is often although not always a child psychotherapist.

Current NICE guidelines (2013, fig 1.3.1) state that psychological interventions should "aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction".

I will now outline thinking on the aims and particular relevance of concurrent parent work for this client group.

Feeling understood and developing understanding

Reid described how the parent worker aims to truly engage with the parents and is open to knowing "how it feels". As the parents hopefully come to feel more understood, they may become more receptive to the clinician's thoughts. "If parents become more contained and reflective in sessions, the child's behaviour may similarly become less anxious, more flexible or more organized” (Urwin, 2011 p249).

Singletary (2015) also stressed the importance of helping parents to understand the inner world of the child with ASD, as understanding helps the child to feel less stressed and anxious about social interactions.

Weakening the bad internal voice

In 2018, Rhode described the idea of a weakening the bad internal voice (Tischler, 1979). Rhode explained that, as the parent sees the child’s improvement, the internal figure is weakened and a “benign cycle can be set in motion” (2018, p717). She stressed the importance of parent work for the sake of both the child and the parents themselves, helping them to understand that the child’s relationship to its internal parents is different from the reality of its actual parents.

Supporting parental capacity

Klauber suggested beginning work with parents with practical help around eating, sleep patterns and toileting which “can begin to restore their own confidence in their role as parents” (1999, p33). From this, some parents begin to think about their own relationships and history and their internal representations, "seeking to understand more about how such a structure may have been affected by the autistic child and may further affect the capacity to parent with confidence" (*ibid*.).

Processing trauma and seeing the child

Klauber described how “the devastating, private tragedy can rock a family’s universe”. She explained how parent work provides the possibility of working lives through and moving on so that parents may be able to “engage or re-engage more closely and clear-sightedly with their child” (1999, p37-38).

Alvarez and Reid (1999) explained the relief many parents feel on discovering “a more robust and ordinary part of their children’s personality hidden among the symptoms, or ordinary emotional needs and behind strange behaviours” (p9). They went on to consider the help parents may need in seeing the part of the child that is enormously needy and hypersensitive rather than indifferent and insensitive.

Klauber (1999) considered that by the time families come in the psychoanalytic treatment, “the parents have already lived with the child and a crazy way of life for a long time" (p35). She discussed the difficulty that such parents may have been managing the normal ebb and flow of hope and disappointment in treatment, where progress is met with great joy, but tiny setbacks are experienced as a huge blow and the progress then wiped out of their minds.

Klauber explained that it is the parent worker’s task to honestly monitor what is a hopeful sign of improvement as well as what is not. She stressed that parents “need someone who will be able, for example, to interpret what is really developmental, but looks like the opposite” (1999 p41). Klauber illustrated this idea by describing a blank but happy child who became more distressed about change.

Increasing communication in the network

Alvarez and Reid (1999) described the difficulties that can occur within the network around children with autism. As this is a communication disorder, there is significant potential for difficulties such as miscommunication and a lack of communication. The family worker aims to liaise with the parents and the wider network including school, speech therapists, paediatricians etc., facilitating and improving communication all round.

Conclusion

This literature review has discussed writing relevant to research question, focussing on defining autism, clinical work in the field, parents’ experiences of autism and place within child psychotherapy.

Significant themes which emerged from the literature are

- views on the appropriateness and value of child psychotherapy for this client group
- the crucial nature of work with parents within the child psychotherapy model

It is evident from the literature search that there is little research or writing that explores parents’ experiences of intensive child psychotherapy, which is the focus of this study.

I will refer back to the work discussed in this literature review in the discussion section of this thesis, placing my findings into the current research context.

Chapter 3 Research Methods

Introduction

In this chapter I will outline the decisions made about the chosen method of research, Interpretative Phenomenological Analysis (IPA), and discuss why this method is appropriate to answer the research question. I will refer to relevant literature in order to support the methodological decisions, discuss IPA's philosophical framework and outline the relationship between IPA and psychoanalytic thinking.

Following this, I will explain how the method was applied, describing data collection, the research setting, the inclusion process and the recruitment of participants. I will describe the development of the interview questions and the interviews themselves.

In the final section of this chapter I will explain the analytic process in detail. I will describe how significant decisions were made about study redesign before continuing with an explanation of each stage of the analysis.

I will end the chapter with conclusions about IPA as a method for analysis.

3.1 Which study design?

My research proposal evolved through discussion with the Tavistock Autism Workshop leader, Louise Allnutt. I took my developing ideas for the project to the Tavistock Research Seminar and discussed these with other students and members of the Tavistock Reseach team (Michael Rustin, Catrin Bradly and Jocelyn Catty). I was particularly interested in the experiences and views of parents of children with autism. I wanted to understand the complexity of parents' relationship to child psychotherapy. In our discussions, we considered how some parents may have experienced improvement in their child's symptoms over the course of therapy but not feel positively towards the intervention, whereas another parent may not have seen any progress, but feel appreciative of the help nonetheless. The research question evolved to be:

How do parents of children with autism who have received intensive child psychotherapy view the treatment now?

I became aware that, in order to capture the complexity of parental opinion, the research design needed to include unconscious material as a source of data. Semi-structured interviews with a small number of participants seemed the most appropriate option, in order to facilitate the parents' free narrative and allow for data analysis at an appropriate depth.

3.1.1 Why IPA

What is IPA?

IPA is a qualitative research method which allows research subjects to tell their story in their own words. The IPA researcher is interested in what a particular person made of a particular experience. As a phenomenological method, it is concerned with experience for its own sake.

The research method is informed by hermeneutics: the theory of interpretation. In-depth descriptions are gathered, usually during interviews, and closely analysed by the researcher. There is said to be a double hermeneutic as "the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith *et al.,* p3).

As the method uses in-depth detail of a particular case, it can be described as idiographic. The sample sizes are typically small to allow for the appropriate depth of study.

The goal of the method is to understand more about phenomena through a specific human experience.

Considering alternatives

In order to try to understand more about different quantitative methods for analysing data, I searched for papers comparing methodologies and also read discussions on relevant online threads such as researchgate.net. Such virtual peer groups allowed me to experience other researchers' decision making processes about their methodologies which in turn helped me to think about my own. I became aware of a variety of qualitative methodologies, such as discursive and narrative approaches, for gathering and analysing data (Smith *et al.,* 2009 p45). The two methodologies which emerged as most suitable for my focus of study were IPA and Grounded Theory. It was important to give some attention to the differences between the methodologies in order to be clear that IPA was the most suitable choice.

IPA and Grounded Theory

I found Starks and Brown Trinidad's (2007) paper particularly useful in helping me understand more about the similarities and differences between these two methodologies. Grounded Theory developed from the field of sociology whereas IPA evolved from European philosophy. In Starks and Brown Trinidad's view, "the boundaries between them are porous" (*ibid.,* p1373). Both methods are concerned with meaning and real-life experiences. The interviewing strategy is typically the same with the research participants describing their experience and the interviewer focusing on detail and clarity.

I came to understand that the aims of the methodologies are different. Grounded theorists hope to understand social structures and processes and how these have influence within a context. Their aim is the development of explanatory theory of basic social processes. Smith *et al.* (2009) considered that Grounded Theory is likely to be of interest if the researcher would like to "move to quite a high level conceptual account" (p44). Rustin and Rustin (2019) described how the method can be viewed as "a way of exploring new phenomena in the light of existing theories, and challenging them in the light of experience" (p20). IPA has a different emphasis. Here the aim is to describe "the meaning of a lived experience of a phenomena" (Starks and Brown Trininidad, 2007 p1373), or as Rustin and Rustin put it, "to capture the experience of subjects, in all their complexity, rather than to develop generalizing theories about them" (2019, p20). IPA seemed a better fit for my research question.

3.1.2 Philosophical framework for IPA

I became increasingly aware of the need to keep in mind the philosophical underpinning for a methodology as my research progressed. I will refer back to this later in this chapter when I describe the study redesign.

IPA was organised into a research tradition in 2009 by Smith, Flowers and Larkin. The method evolved from three areas of philosophy, namely phenomenology, idiography and hermeneutics. I will now briefly outline how I have understood each area.

Phenomenology

Phenomenology is a philosophical school which became established at the beginning of the 20th century. Its key thinkers - Husserl, Heidegger, Merleau-Ponty, and Sartre - were interested in building a secure foundation for knowledge. Husserl described his views on how objects or events are perceived by an individual, the “experiential content of consciousness” (Smith *et al*., 2009 p12). Sartre explored the developmental aspects of human beings; that the self is an ongoing, evolving project, or as Kierkegaard (1974) put it, “an existing individual is constantly in the process of becoming” (p79). Phenomenology’s primary position is that “the most basic human truths are accessible only through intersubjectivity, and that the person is integral to the environment” (Flood 2010, p7).

Idiography

An Idiographic approach to knowledge is one that is concerned with what is unique and specific, as opposed to a nomothetic approach which focuses on a generalised view. The terms were used by Windelband (1895), a follower of Kant who rejected scientific reductionism.

Hermeneutics

Hermeneutics is the study of interpretation, of understanding and making oneself understood. It draws on the work of Schleiermacher, Heidegger and Gadamer. Focus is on the relationship between the ideas of the researched and those of the researcher. Zimmerman described how hermeneutic thinkers consider that “understanding is the interpretive act of integrating particular things such as words, signs, and events into a meaningful whole” (2017, point 5). Understanding only occurs when a word or fact resonates meaningfully and makes sense to our lives.

Smith *et al.* (2009) considered the concept of the hermeneutic cycle particularly important. Here the focus is on “the dynamic relationship between the part and the whole” (p28). Smith *et al.* described how this idea is relevant in an IPA study at many levels, a single word/the sentence, a single extract/the complete text, the interview/the research project, the episode in the participant’s life/the whole life. (*ibid*.)

3.1.3 IPA and psychoanalysis

Tensions between IPA and psychoanalysis

Smith, Flowers and Larkin (2009) cautioned against using a psychoanalytic frame in the research context, believing it goes beyond the boundaries of IPA. They pointed out the danger of researcher bias, suggesting that the psychoanalytic researcher may rely on “a pre-existing formal theoretical position” (Smith, 2004 p45) that could influence selection and interpretation of data; importing ideas from “outside” rather than staying grounded “inside” the text. Midgley (2006) addressed the same common criticism of psychoanalysis in research, adding that such a frame “does not allow for an interpretation to be proven wrong … thus rendering its results self-fulfilling” (p216).

Through my reading, I came to agree with McGregor Hepburn’s (2018) reflection that IPA as a methodology appeared to be offering the possibility of using psychoanalytic thinking and skill but at the same time warned against relying on such ideas as they could possibly interfere with the analytic process. It felt important to understand more about reflexivity and the double hermeneutic and how these relate to psychoanalytic concepts of transference and countertransference. I found Wendy Hollway and Tony Jefferson’s (2013) *Doing Qualitative Research Differently* particularly helpful in informing decisions about using psychoanalytic observations as a form of evidence within IPA.

Reflexivity and the double hermeneutic

In IPA, the primary concern is “the lived experience of the participant and the meaning which the participant makes of that lived experience” (Smith *et al.*, 2009p80). The methodology draws on the work of Gadamer (2004) who believed that understanding is interpretation and vice versa. The end result of an IPA analysis is “an account of how the analyst thinks the participant is thinking” (Smith *et al.*, 2009 p80). This is the double hermeneutic.

Researcher reflexivity is considered central to IPA as a tool for understanding meaning. Smith *et al.* defined researcher reflection as “the attentive and systematic examination of the content of consciousness, our lived experience” (2009, p16). Ahmed (2004) explained how reflexivity requires a double turn, a turning towards and then away. The challenge is to get to know the research participant and at the same time remain sufficiently separate. Smith *et al.* (2009) explained that both empathetic and questioning stances are required for a successful IPA analysis.

Psychoanalytic concepts – transference and countertransference

Hollway and Jefferson (2013) focussed on the role of the researcher in how qualitative data is produced and analysed. They explained "the unconscious intersubjective dynamics in the interview relationship" (p4) and referred to being attuned to the "unconscious 'embrace' of another person" (p65) with sufficient distance to think.

The key psychoanalytic concepts of transference and countertransference were defined by Hollway and Jefferson in the following way: "Transference refers to the unconscious transferring of other emotionally significant relationships on to the therapist by the patient; countertransference to the therapist's responses to these transferences, as well as their own transferring of emotionally significant relationships on to the patient" (2013, p44). They considered that their use of these concepts in qualitative research was not identical to how they are used in clinical psychoanalysis and as such, the research might be better termed "psychoanalytically informed" rather than "psychoanalytic" (p150). Hollway and Jefferson explored using alternative phrases for the researchers' processes such as Hunt's (1989) "using subjectivity as an instrument of knowing" or simply using one's emotional responses (Urwin, 2007b).

Bracketing off

The concept of bracketing off, as described by Smith *et al.* (2009), is derived from Husserl's aim to achieve a phenomenological attitude. Husserl (1927) described the need to put to one side, or "bracket," that which is taken for granted. The intention is "to lead the enquirer away from the distraction and misdirection of their own assumptions and preconceptions" (p14) so that the essence of an experience of a phenomenon can become more clearly in focus. The idea of bracketing has its roots in mathematical equations, where the contents of brackets are treated separately. I found this mathematical image helpful as it illustrates the idea that there is no attempt to delete bracketed material, but rather acknowledge it and put it to one side for later consideration.

The concept of bracketing appeared to sit comfortably with the child psychotherapy training, where students learn through their personal analysis, individual and group supervision to identify and separate out feelings and responses that come from their own internal world from those communications which belong to their patients. In a researcher role, it felt important to use similar capacities, through careful observation, to identify preconceptions and feelings belonging to the researcher, which would detract from the field of enquiry, and bracket these off. Conversely, those emotional responses which were identified as belonging to the participant were seen as important communications providing illuminating additional evidence and as such were an integral part of the application of the method as I will now explain.

Psychoanalytically informed IPA

Alongside discussions in supervision, I raised the question of using psychoanalytic skill and thinking as part of an IPA research project in the regional IPA study group, held at King's College London and attended by IPA doctoral students across a variety of psychological disciplines. The general consensus was that psychoanalytically informed observations were a valid form of evidence because the researcher, as an integral part of the process, is a child psychotherapist.

I agree with Hollway and Jefferson that the application of the psychoanalytic concepts of transference and countertransference is different in a research setting and as such I found it helpful to use different language such as "my emotional response" (MER). This created a sense of freedom and enabled me to avoid becoming too wedded to psychoanalytic ideas which was considered a potential weakness in psychoanalytic research by Krause and Cooper (2019).

Transparency

As Larkin stated, "the researcher functions as a channel or filter through which the experiences are conducted – and constructed. Some account of this side of the process should be included in your analysis" (Larkin, 2018 slide 67).

Being transparent about the thinking and skills used in gathering and understanding the data is congruent with IPA and arguably preferable to considering such knowledge as a preconception that should be bracketed off. Such transparency allows the critical reader the opportunity to assess the researcher's processes, including any bias or tendency to impose external theory.

Deepening the data

Using one's emotional responses and observations of unconscious communications provides an opportunity for deepening of the data. As Donaghy (2017) explained, there can be a "deeper exploration of the respondent's experience, including areas of internal experience" (p224).

As well as describing the value of using the researcher's emotional responses in research, Hollway and Jefferson (2013) noted difficulties if this kind of data were not included. As McGregor Hepburn explained, "Without the application of other evidence from the texts, the patterns of speech and the emotional tone, what may be seen could be only a small part of the whole" (2018, p62). Hollway and Jefferson referred to a study by Sue Jervis which used the researcher's embodied emotional response, a physical reaction, as relevant data. As Jervis noted, "Had I not reflected upon the unusual sensation that I believe Karen [the participant] unconsciously communicated to me, it is possible that this dynamic might have remained hidden, limiting research findings" (Jervis, 2009 p149). This kind of communication from the respondent could be considered the next level. It would be a lost opportunity to exclude it.

Evidence within a context

Jervis (2009) stressed the importance of not relying on one source of evidence, particularly as there are limitations for trying out researcher's interpretations with participants, "they should be careful not to make any interpretations based upon the feelings evoked in them unless those interpretations are supported by other evidence within the research material" (p155). McGregor Hepburn (2018) wrote about the slow, tentative building up of understanding, including use of the researcher's own responses, as a form of triangulation.

My approach involved meaning, and understanding of meaning, evolving slowly through paying attention to different sources of evidence as they corroborated each other, or not. Because of the tension between IPA and psychoanalysis, I was acutely aware of the need to provide clear evidence for my thinking so that my processes could be reviewed by others. I observed language, content, emotional and physical communication throughout the data collection and analysis. I was open to how content was delivered, such as pauses and stumbles. As McGregor Hepburn noted, "what is left unsaid may be as significant as what is said in the lived experience of the participant” (2018, p60). I paid attention to feelings that “were unwanted, denied and/or felt to belong to others” (Lucey *et al*., 2003 p282). I attempted to observe myself observing while keeping in mind the possibility of focusing too much on myself and losing sight of the subject. This imbalance in focus was highlighted as a potential danger for the psychoanalytic researcher by Krause and Cooper (2019). I tried to notice when I thought like a psychotherapist and not dismiss this, but see such thoughts within a context of other possibilities. I will expand on sources of evidence later in this chapter.

Further thoughts on triangulation

As McGregor Hepburn (2018) described above, the slow building up of meaning is a form of triangulation based solidly on the data and integral to the analytic process. As the emotional responses of the researcher and psychoanalytically informed observation were an integral part of the methodology, supervision and peer reflection were important for triangulation during the analysis. Hollway and Jefferson (2013) stress the need for time, containment and the support of others. In my case these opportunities were provided through supervision, attending the quarterly regional IPA peer study group and using the online IPA discussion forum (ipaqualitative@groups.io), with 2,390 members, which is often active on a daily basis. Each of these forums provided an opportunity to “go beyond the idea of the defended researcher by focusing on how to help researchers reflect when their thinking is in danger of being compromised by their anxieties” (Hollway and Jefferson, 2013 p166).

It was particularly helpful and aided triangulation to have supervisors from two different disciplines, child psychotherapy and clinical psychology, providing differing perspectives on the research. Supervision helped me to notice when I was drifting into thinking like a clinician rather than a researcher. Comparison was drawn with the state of mind needed at the beginning of an infant observation, “beyond memory and desire” (Bion, 1967).

I will discuss the triangulation of the research findings further in chapter 6 when considering theme validity.

3.1.4 Conclusion

Like the human self, IPA is an evolving methodology, “constantly in the process of becoming” (Kierkegaard, 1974 p19). There is no correct way to apply it. The challenge is to be open, rigorous and ready to be surprised. Hollway and Jefferson (2013) saw a parallel within psychoanalysis, “from treating transference and countertransference responses in the analyst as an obstacle to knowledge, to using them as a resource for understanding that could not be achieved through cognitive analytic kinds of knowing” (p166). They recognised a similar debate in psychosocial research where attention is being given to how the researcher’s emotional responses can be used to “enhance their understanding of what is initially beyond words” (p166). The authors saw this as a momentous change in perspective.

3.2 Data collection

This section of the chapter focuses on how the data was collected.

Reflective journal

In order to capture my thoughts, I wrote a reflective journal after any study activity. In supervision we discussed the importance of having this record of my thoughts and feelings through each step of the research process, enabling me to become more aware of and refer back to my observations, preconceptions and preoccupations. I will draw on thoughts from the reflective journal later in the discussion chapter.

I will now describe the process for recruiting and collecting data from the study participants.

3.2.1 Participants and research setting

Research setting

Only a small number of families with a child with autism have been offered and participated in intensive psychotherapy. For this reason, I originally considered basing the research in more than one setting, i.e. two NHS clinics and a school, in order to increase the chance of recruiting participants. However, I decided, with the help of the Tavistock Research Seminar and through supervision, to base the research in one NHS clinic in order to recruit a reasonably homogenous sample.

Eligible cohort and purposive sampling

The cohort was identified using the inclusion criteria in figure 1. This was developed through discussion in supervision and at the Tavistock Research Seminar.

Figure 1: Inclusion criteria

- Aged under 10 years at start of treatment
- diagnosis of ASD or strong autistic features in a related diagnosis
- minimum of one year of intensive therapy
- minimum of six months and maximum of seven years from the end of therapy at the point of interview (follow up)

It was hoped that the eligible cohort would include a range of predicted parental opinions. I planned to use maximum variation purposive sampling to select five cases from this cohort in order to include a range of perspectives in parents. In this way I hoped to add to the depth of the study by examining multiple perspectives on a shared experience. We intended to use an analysis of the clinic's routine outcome measures, as well as the therapists' termly summaries and letters, to help predict possible parental opinion. However this aspect of the study became unnecessary as will become apparent.

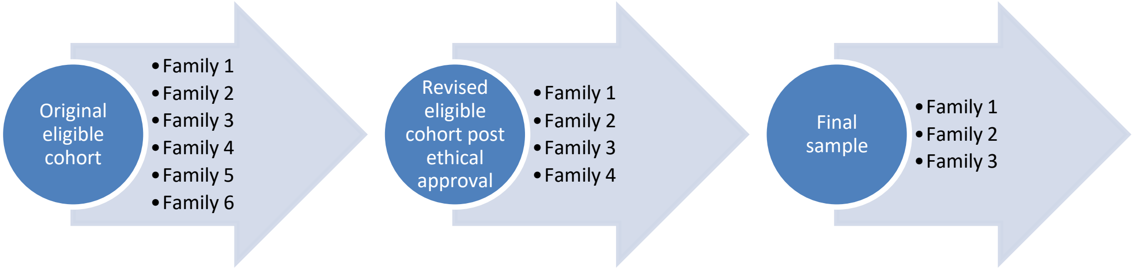
The eligible cohort was identified by my supervisor for ethical reasons. This process, along with how families were contacted, will be explained in the research ethics, chapter 4.

An initial investigation indentified six cases as potentially eligible for the research. Access to the families and clinicians in each case had been considered and it seemed likely that the potential participants would be available for study. The ethics process took longer than originally predicted and by the time ethics approval was granted, family 6 were no longer eligible as it was now over seven years since the child's intensive therapy ended. Family 5 were also ineligible because, although originally the child was expected to end intensive therapy in time to be included in the study, a clinical decision was made to continue the intensive work. Four families therefore remained. It became unnecessary to predict the opinion of parents to inform sampling as a sample size of four was considered appropriate and all the remaining families would therefore be included in the research.

Recruitment

Four families were sent information about the study (see appendix A and B). All of these families initially expressed interest in being involved and were happy to be contacted directly by the researcher. I was then able to make contact with three of the families. The fourth family did not respond and, after a number of attempts, a decision was made to cease contacting for ethical reasons. The process for informed consent will be discussed later. Three families remained in the final sample. Figure 2 illustrates the recruitment process.

Figure 2: Recruitment process



Sample size

Although I was initially concerned about whether a sample size of three was sufficient, discussion in supervision and at the regional IPA meeting provided opportunities to recognise that a small sample size would allow a close examination of the parents' experiences and the meaning they made of them. As Starks and Brown Trinidad (2007) put it, "Although diverse samples might provide a broader range from which to distil the essence of the phenomenon, data from only a few individuals who have experienced the phenomenon - and who can provide a detailed account of their experience - might suffice to uncover its core elements" (p1375).

Participants

The families who agreed to be part of the study are presented in the table below (figure 3). I planned to interview the parents who were involved in the parent work accompanying the therapy. In each case, this resulted in mothers agreeing to be participants.

The mothers from families 1 and 2 are white British. The mother in family 3 is an immigrant from an African country who speaks English as a second language. All of the participants appeared to be educated to a high standard.

As a white, British professional woman, it was important to recognise thoughts about differences and similarities between me and the respondents. As Watt (2019) reflected, “Cultural influence is a powerful organizing thread that runs through any research process, as it does through all our lives” (p191). I aimed to notice and question when I thought I knew something of another’s experience due to perceived similarities in race, culture and class. I strived to remain open to the experience of a black woman being interviewed by a white woman, not in her native tongue. (It is noteworthy that for family 3, the clinicians in the psychotherapy treatment were also white). Like Hollway and Jefferson (2013), I was interested in “how relational dynamics, such as understanding and respect, have the capacity to transcend structural power differences” (p79).

A thorough exploration of the impact of differences in race and culture in research was beyond the scope of this thesis. Throughout the research process I will refer to moments when questions about similarity and difference came to the fore.

Figure 3: Participants

Participant	Gender of child	Child’s age at start of treatment	Child’s use of language	Duration of intensive treatment	Follow up
Family 1 Mother participant	M	6	Verbal	1 yr 8 mths	1 yr 4 mths
Family 2 Mother participant	M	3	Verbal	1 yr 7mths	3 yrs 8 mths
Family 3 Mother participant	F	4	Non-verbal	2 years	1 yr 5 mths

3.2.2 Interviews

Development of interview questions

In supervision, we considered a number of different ways to develop appropriate interview questions, such as approaching a parent group based at the clinic with some potential questions for discussion and opinion. Another possibility was to gather a group of child psychotherapy clinicians who had worked with families with children with autism in order to develop questions. Unfortunately, both of these options proved too difficult to coordinate due to time constraints.

Peer discussion

It was possible for me to arrange a meeting with a child psychotherapist who has considerable experience of work with parents of children with autism. I will not name the clinician in order to protect the anonymity of her patients. As well as developing interview questions, the aim of the discussion was for me as a researcher to reconnect with this clinical area as I had not worked with families with children with autism for some time. I was also keen to learn more about the concerns of colleagues currently working in the field. I found the discussion extremely helpful. Following the development of the parent interview questions, I bracketed off this peer discussion until after the participants’ data analysis was complete, whilst staying aware of its influence on me. I will draw on the discussion in chapter 6 in order to provide further context and triangulation for the research findings.

Following the peer discussion, I read Smith *et al.* (2009) to explore the kinds of open questions which can be helpful in semi-structured interviews. In this new researcher role, I recognised some anxiety about having enough questions and prompts to facilitate my participant to tell their story, whilst also holding in mind the need not to lead or direct.

Peer review

Through supervision, I decided to use the same questions for each interview with flexible prompts ready when applicable for individual participants in the moment. I prepared a document to explain the study and outlined the proposed interview questions and prompts (see appendix C). I sent the document to eight child psychotherapists who work with children with autism and their families, asking for comments. I received four responses from clinicians who felt the questions were well worded and suitable for the aims of the study.

Schedule of activities

As suggested by Smith *et al.* (2009) I arranged the parent participant interviews with enough time between them to allow for transcription and an initial coding of each interview, before putting that experience to one side and moving on to the next participant. I paid attention to how the experience of the first might influence the second and subsequently the third and made notes about these thoughts in my reflective journal.

3.2.3 Parent interviews

I aimed to conduct the interviews at the NHS clinic however I allowed for the possibility of home visits if interviews at the clinic were inconvenient for the family. Alase (2017) stressed the importance of allowing participants to decide on the date, time and place for the interviews, describing, “the participants’ place of comfort” (p15). The choice of interview setting had significance and will be discussed later.

I carried out three parent participant interviews between November 2017 and February 2018. Immediately before each interview, I reflected on my preoccupations and concerns, recording my thoughts for later transcription into my journal. At the beginning of each meeting, I explained that I was interested in anything the participant wished to tell me about their experience and that my questions were simply a guide to that end. I audio recorded each interview.

The interviews lasted for one hour. I allowed for an option of a second interview with each parent if the information I hoped to gather had not been discussed in the first instance. In practice this was not necessary.

3.2.4 Clinician interviews

As well as interviewing the parents, I originally intended to gather the views of the clinicians for each case (child's therapist and parent worker) through a brief 15 minute interview along with studying any available validated outcome measures, letters and summaries of each term's work. However, this element of the study was subject to significant revision which will be outlined below as it occurred in the research process.

3.3 Data analysis and study design decisions

I will now describe how the data was analysed. I based my methods on the detailed description of process in Smith *et al.* (2009) and Larkin (2018). I will describe and illustrate each stage below.

3.3.1 Analysis A

The aim of analysis A was to capture my initial responses and reflections on the data. I kept in mind advice from Smith *et al.* (2009) and from supervision to write down my thoughts free from rules as to what I perceived to be expected or desired.

Analysis A involved four stages which are illustrated in the table below (figure 4).

Figure 4: Stages of analysis A

Stage of analysis A	Activity	Time frame
(a)	Initial reflections recorded verbally	Immediately post interview
(b)	Interview transcription with reflective commentary	Shortly after interview
(c)	Repeated listen to the interview, adding to the commentary	After all three interviews were completed
(d)	Repeated read of interview transcript, adding to the commentary	After all three interviews were completed

The first step was to record my thoughts immediately after each interview (a). Here I reflected on the moments in the interview which were particularly emotionally powerful, my initial impressions and my state of mind following an hour spent with the participant. An example is given in figure 5.

Figure 5: Extract from reflective journal post interview - family 1

I felt very warmly towards this mother. She was able to really talk about her experiences. She was extremely generous and I wondered if this was because she was so grateful for the work they had received as a family and how significant it was for them.

She spoke about some very painful subjects. It was really striking how she described her son as being behind a wall of glass and both parents feeling that they would never really know him.

She described the sessions as her psychotherapy rather than parent sessions. Her descriptions of how painful it was to end the work for herself were extremely powerful.

Over the next few weeks, I transcribed the participant interview, writing my reflections in a commentary alongside the transcription (b) as I went. Transcribing interviews myself allowed me to think in great detail about what the participant was saying and how they were saying it, as well as the feelings in the room and my responses as I re-experienced the material. Other psychoanalytic researchers have noted how transcribing interviews personally can help the researcher to get closer to the participants' experience. (Holmes 2012; Watt 2019) As I listened to each phrase in the audio recording, I spoke it into a microphone and it was then turned into text by dictation software. I had become very familiar with this method of transcribing during my training as a child psychotherapist and found it particularly valuable for digesting content and experience.

My commentary notes, also dictated, included summarising content, associations, connections, echoes, repeats, contradictions, the participant's choice of language and style of delivery. I also noted my sense of the person, any preconceptions I observed in myself (Smith *et al.,* 2009 p67) and my emotional responses (MER) to the material. Speaking my thoughts in this way, rather than writing them, appeared to aid free association, allowing ideas to flow rather than be formed into written text.

In order to allow each interview to fill my field of vision and be as much as possible a separate and unique experience, it felt extremely important to capture my reflections in as much depth as possible before I moved forward to the next parent's experience.

Following stage (b), I moved on to the next participant. It was not possible to complete all four stages of the analysis on each case before progressing to the next interview as each stage of analysis A took a considerable amount of time to complete. Having contacted the families, it was not advisable to wait many months before conducting the interview.

Having completed all three interviews along with analysis A (a) and (b), I returned to each case and continued with the next stage of analysis A (c) and (d) adding to my commentary with further reflections on the data. I used different coloured text in order to keep track of when and how my thoughts had surfaced in the reflective process. It was interesting to note my different responses when reading the transcript as opposed to listening to it. Listening back to the interview was particularly effective in allowing me to re-immerse myself in that participant's particular experience, bracketing off the other parent interviews. An example of analysis A is shown in figure 6.

Figure 6: Extract from transcription and commentary – family 2

Minutes	Transcription	Commentary (b) (c) (d)
3-5	Erm, and so, I mean it's a lot of, I remember it being a lot of effort, it's a big investment in time and it just happened to be during that time I wasn't working. I can't remember if I was at the back-end of maternity leave from Samuel and then, because the city is really great about people having babies you then get fired so (laugh) I was then job hunting, so even though it was not great for me from that point of view it was actually good because I was around a lot more than I would have been had I been working so I was able to come to the sessions and stuff ...	She spoke about the enormous commitment to 3 times weekly work. I thought about how it must be with the small baby and a young child to fit that into your week. Really something, and therefore even more striking that she was keen to stress her indifference to the intervention. The way she spoke about getting fired from the city after having a baby was matter-of-fact, just part of a conversation. It was actually quite shocking when I realised what she'd said. She laughed at my response which was rather taken aback. She had a way of saying something shocking, without emotion. I was struck by her talk about needing to find a job. (I had begun to think that perhaps the other woman in the apartment was a nanny). My assumption was that there was a father who would be earning a significant salary. I did not realise at this point the crucial nature of her employment status. Psychotherapy a big commitment – she was available Punishment for having a baby – being fired from her job. A lot of effort Came at a hard time for her – two small children and no job Convenient rather than desired

I was aware as I was carrying out this extremely time consuming process of repeated listening and reading that I was being very thorough and there was a danger in expanding the data too far. However, it felt important to develop a process that would capture the feelings in the moment but also allow time for thinking to develop. Repeated reading and listening allowed the opportunity to identify and bracket off my preconceptions (such as the highlighted section above) and to allow myself to be wrong (Larkin 2018, slide 44).

I completed analysis A on all cases before moving to analysis B. This was in order to avoid any awareness, as much as possible, of emerging themes whilst interviewing as this would have been an unhelpful distraction.

3.3.2 Study redesign

When it became clear that family 4 were no longer available as part of the study, I considered the sample size in supervision. I was concerned about whether three families were enough. We discussed the possibility of expanding the interviews with the therapists and parent workers in each case. As Smith *et al.* (2009) explained, “one phenomenon from multiple perspectives can help the IPA analyst to develop a more detailed and multifaceted account of that phenomenon” (p 52). I was aware of another psychoanalytic researcher who had used this approach in her IPA study (Serlin, 2017).

I proposed expanding the clinician interviews from the original 15 minutes to 50 minutes and submitted a non-substantial amend form, with revised clinician PIS and consent form (see appendix D and E), to the regional ethics committee which was granted approval. With these expanded interviews in place, it was no longer necessary to view termly summaries and outcome measures to gather clinician opinions and therefore this element of the design was discarded.

At this point in the process, I arranged interviews with the child’s therapist in each of the cases, prioritising the therapist over the parent worker as the clinician most connected to the clinical work. I decided to complete analysis A (c) and (d) for each family before interviewing each of the therapists in order to keep my focus on the parent participant’s unique experience. The order of events can be seen in figure 7.

Figure 7: Interviews – order of events

Family 1 – parent interview – analysis A (a) and (b)
Family 2 – parent interview – analysis A (a) and (b)
Family 3 – parent interview – analysis A (a) and (b)
Family 1 – parent interview – analysis A (c) and (d)
Family 1 – therapist interview – analysis A (a) and (b)
Family 2 – parent interview - analysis A (c) and (d)
Family 2 – therapist interview– analysis A (a) and (b)
Family 3 – parent interview – analysis A (c) and (d)
Family 3 – therapist interview – analysis A (a) and (b)

3.3.3 Expanded clinician interviews

I developed interview questions for the therapist interviews in much the same way as the parent interviews. Keeping in mind the areas of enquiry (see figure 8), I developed open questions and prompts and introduced the interview explaining that I was interested in anything they wished to tell me about their experience, with the questions only to facilitate reflection.

Figure 8: Areas of enquiry

Therapists' understanding of and feelings about

- the intervention with children with autism
- the child's experience of the intervention
- any changes during and after the intervention
- parents' relationship with the intervention – before, during and after
- parents' use of parent sessions

I reviewed the questions in supervision (see appendix F). Each interview lasted 50 minutes and was undertaken in each of the therapists' place of work. In supervision, we decided to undertake analysis stages (a) and (b) only as to proceed beyond this would generate an unmanageable amount of data.

3.3.4 Annual Review – narrowing the study focus

At this point in my research I had an annual doctoral review on the progress of my study, with Jocelyn Catty and Brinley Yare. The review gave rise to the question of whether comparing differing perspectives (parents, therapists, parent workers) was in fact compatible or desirable with the IPA method. Yare argued that an understanding of what the therapist and parent worker thought about the child's therapy would not take us closer to parent's experience and could well work against it as a dilution of attention. In IPA, there is no unitary experience. Yare referred to the existential therapist Hans Cohn (1997) whom he felt captured IPA's core epistemological tenants when describing the therapist's first meeting with a client. Cohn described how the client the therapist meets is not the same client a different therapist would meet. The account the client gives is only that; they may say something quite different to another therapist. Cohn warned against taking a "history", explaining that "history is disclosed in the process of interaction between therapist and client" (1997, p33-34). There could not be an "assessment" as this would suggest an "objective situation independent of time, place and the contribution of the assessing therapist" (*ibid*.).

The doctoral review and subsequent supervision highlighted the need for me to understand more about the philosophical underpinnings of IPA. I decided at this point to join the IPA online forum and began to attend regional IPA meetings.

In supervision we considered the options. Crucially, we returned to the research question which does not contain any element of comparison, but focuses on parents' views. I was keen to work in as much depth as possible and give my full attention to each unique parental experience, to "go back to the things themselves" as Husserl famously argued (Smith *et al.*, 2009 p12).

Regarding the sample size, Larkin (2018) proposed that: "The question is not 'how many participants do I need?' – but 'are these data adequate to the task?' i.e. Are they rich enough?" (slide 35) In my research, the parent interviews had provided extremely rich data and as such three participants were considered appropriate. We decided that a thorough analysis on a small sample would allow for greater depth of inquiry.

A decision was made against conducting any further interviews with parent workers and instead I returned to focussing on the parent interviews. I would bracket off the therapist interviews for this study and consider them again only after the analysis was complete.

I will now return to the analysis of the parent participant interviews. In the analytic process, I was now able to immerse myself in each participant's data for analyses B, C and D before moving on to the next.

3.3.5 Analysis B

Analysis B was the beginning of condensing the data by capturing the emerging themes. The aim of this stage in the analysis is to produce a slightly higher level of abstraction, keeping in mind that, "At the same time, the thread back to what the participant actually said and one's initial response should be apparent" (Smith *et al.* p68). This is called descriptive or phenomenological coding.

We planned that I should attempt analysis B on a small section of data and take this to supervision for discussion. My initial attempt was, in line with most IPA novice researcher's experiences, too descriptive and required a shift towards the conceptual. My supervisors also felt the analysis had a quality of clinical responses rather than those of a researcher. Following this reflection in supervision, I took away advice to focus on feelings such as "fear" and "disappointment" and move away from clinical language such as "high levels of anxiety". I considered how I might proceed. I arranged a meeting with a peer child psychotherapy IPA researcher who generously talked me through her process. I also attended two regional IPA meetings before continuing with analysis B.

The IPA online forum included discussions on using software to help manage coding and themes. A number of students recommended Microsoft Excel for small scale IPA analyses. I took some online tutorials to help develop my skills in Excel and then designed a table to allow for a line-by-line consideration of the transcript data. See figure 9 for an example.

I listened to each interview again in two minute sections so as to focus on the way the participant delivered the material and to reconnect to the feeling in the room. I noted significant phrases/words in red. Alongside this I studied analysis A, checking the responses I had had to the data for validity and bracketing off any preconceptions (such as in figure 6) or reflections which felt unsubstantiated. I highlighted language which seemed to link to other language in the text.

I noted feeling states/experiences and then linked back to the participant data with a note of which source or sources of evidence supported the feeling/experience. As I continued, I clarified my sources of evidence which are described in figure 10.

Figure 9: Example of analysis B – family 3

Min	Transcript	Commentary	Feeling/experience	Source
	A Um, I do remember that lady was wonderful and	Gratitude	Gratitude	Content
	R Do you, do you remember her name?			
	A Yes I do of course. Her name's S. She was such a wonderful	I feel relief that she is talking. Am struck by her clarity	Relief/understanding	MER
	lady and J, because of her condition, was difficult to get on	and how her way of speaking is easy to understand/clear		
	well with a person for the first time, but after the, the third or	I feel warmth when she mentions S - present tense	Love for therapist	MER
	fourth session,	I thought A was going to say J was difficult to get on with	Relationship with J	Association/lang
3 - 5	J started to build up a very nice, good relationship with her.	Importance of relationship - value of third?	Relief	Content
	As soon as we come into the building she knows which door S	Welcomed and included	Included/welcomed in	Association
	will come from, so she immediately rushed to the door and	Sense of child/tuned into anticipation + desire/non-verbal		
	waited and she was eager to go with her to the room and play,	Eager for help	Eager for help	Association/cont
	explore things, and they spent lone hour or like 50 minutes and	Detail		
	J came feeling happy, relaxed. And I could sense that may be	A's desire projected to avoid ending	Avoiding loss	Association/proj
	she wanted to stay more with her.			
	Sadly, she left after one, one year. I was in tears when she left	Loss	Loss	Language
	and I guess J, of course J is non-verbal. She, she hasn't	Hope - is this unrealistic? Had a hollow feeling - not bearing	Avoiding loss	Language
	spoken yet.	Loss		
	But I could sense that J just felt that she is not there anymore,	Ending means blank - not there. Nothingness	Nothingness	Content
	and then there was a gap of like one or two weeks and then	Nothingness/emptiness, then "full" and "lots"	Nothingness	Language
	we had another psychotherapist. Her name's R. Again she			
	worked with J for one year or so. She was, she was absolutely	Negating anger/criticism of being left and not being S?	Negating criticism	Language
	(pause) good with J,		/anger	Delivery
	Yeah. I attended like one or two sessions with them here in the	Included	Included/welcomed in	Content
	building. And I could see how effective it was because the	They showed me	Being able to see	Language
	room was			
	full of lots of toys and games and at the beginning J was	Needed to fill the gap	Avoiding loss	Association/cont
	playing with things not in a meaningful way.		Importance of meaning	Content

Figure 10: Sources of evidence

Content	What is being talked about
Delivery	Pauses, fluency, volume, stresses
Use of language	Repeated words, choice of words
My emotional response (MER)	My feeling response in the moment
Associations	Links to something else the participant has said, ideas, projections, imagery

Gradually, themes began to develop in the feelings/experience column. A theme gained validity if supported by more than one source of evidence. This meant that my emotional responses (MER) were supported by other evidence and not relied upon in isolation but as an additional source of evidence, adding depth and validity to a developing theme. Having reached the end of the interview, I moved on to analysis C.

3.3.6 Analysis C

The aim of analysis C is to identify “emergent patterns and commonalities” (Larkin, 2018 slide 49). Larkin advised researchers to use their psychological knowledge at this stage and consider meaning for the participant within this context. This is “Interpretative coding” (*ibid*.).

For me, analysis C involved listing the feeling/experience themes, initially chronologically. This was column four in figure 9. Figure 11 illustrates the first 50 of a total list of 285 feeling/themes for family 3.

Figure 11: Chronological ordering of feeling/experience themes

Chronological ordering of feeling/experience themes
Discomfort
Too hot to handle
Discomfort about difference
Can you understand?
Not enough
Diagnosis is central – loss
Not sure
Loss and avoiding loss
Critical
Negating criticism
Crucial help
Intensely unsure about help
Loss
Gratitude
Relief and understanding
Love for therapist
Relationship with J
Relief
Included/welcomed in
Relationship with J
Eager for help
Avoiding loss
Loss
Avoiding loss
Nothingness
Nothingness
Negating criticism/anger
Included/welcomed in
Being able to see
Avoiding loss
Importance of meaning
Being able to see
Rejection
Bring in change/3rd
Meaning and knowledge
Linking up
Feeling included
Getting something back/ relationship with J
Joy
Connecting up
Understanding /being able to see
Relationship with J/autism
Crucial change
Linking up
Relief and hope
Meaning
Gratitude
Good things inside here
Relationship with J
Being able to see

The next step was to group the feeling/experience themes into clusters. I did this by colour coding the themes which seemed to belong together. An example of three clusters (from a total of 12 for this participant) is shown in figure 12.

Figure 12: Example of three colour clusters of themes - family 3

Eager for help
Desire for connection
Seeking help
Desire for knowledge/life
Desire for connection
Desire
Intense need
Desire
Surprise and engagement

Something unbelievable
Something unbelievable/unexplainable
Nothing solid
Nothing solid
Nothing straightforward
Can you see?
Something unbelievable
Fragile
Confusion
Fragile
Unexplainable
Fragile
Unknowable
Indescribable
Something in the way

Too hot to handle
Shock
Desperate overwhelm
Unbearable
Unbearable
Shock
Something mad
Devastating loss
Devastating overwhelm
Unbelievable devastation
Devastating overwhelm
Overwhelm
Traumatic shock
Traumatic shock
Powerful shock
Devastating blow
Devastating blow
Shock - loss of function
Extreme loss
Trauma
Loss of control
Trauma
Need for containment

Each colour cluster (emergent theme) was analysed in turn. Following direction from Smith *et al.* (2009, p96-98) I designed a new table for this purpose. The headings are explained in figure 13.

Figure 13: Analysis C – analysing colour clusters

Heading	Definition or example
Feeling/experience theme	E.g. “eager for help” from Fig. 12
Text example	Illustrative quote (or other evidence if shown in italics) from the transcript
Text line	Number of the line of text in analysis B
Contextualisation	Contextual or narrative elements
Abstraction	Putting like with like and developing a new name for the cluster (emergent theme)
Subsumption	A feeling/experience acquires greater status, bringing together a series of related themes
Polarisation/links	Oppositional relationships/links to other emergent themes
Numeration	Frequency of the theme
Function	Function of the emergent theme within the transcript

I traced each feeling/experience theme within a colour cluster back to the transcript and reconsidered it. This process involved considerable adjustment as it became apparent that a theme was better suited to another cluster or that two clusters should join and become one. Each cluster was given a name either by abstraction or subsumption, defined above. I retained the colours at this stage to aid clarity. Figure 14 illustrates the analysis of one theme cluster for family 3. At the end of this process, this theme cluster acquired the name in red, *life-changing shock.*

Figure 14: Analysis C – example of one theme cluster analysis - family 3

Theme	Text example	Line	Contextualisation	Abstraction	Subsumption	Polarisation/ links	N	Function
Too hot to handle	*A spoke about the heat in the room*	5	Relationship with autism	**Life-changing shock**	Desperate Overwhelm	Unsteady foundations	23	Communicating devastation
Shock	*MER - I felt shock*	124	Rel. with me			Loss		
Desperate overwhelm	I just kept buying lots of toys, lots of things	127	Rel. with autism			Death		
Unbearable	How to be cooperative	129	Rel. with autism					
Unbearable	Crying, screaming, like making lots of tantrum	148	Rel. with autism					
Shock	*MER - I felt shock*	163	Rel. with me					
Something mad	Maybe people look at me as somebody	185	Rel. with autism					
Devastating loss	It was very devastating for me when I just heard it	202-3	Rel. with autism					
Devastating overwhelm	I think I talked a lot	220	Rel. with me					
Unbelievable devastation	Devastation of giving the diagnosis	233	Rel. with autism					
Devastating overwhelm	I was in distress	237	Rel. with autism					
Overwhelm	Concrete detail in the face of overwhelm	291	Rel. with autism					
Traumatic shock	My child, erm, my life completely changed	313	Rel. with autism					
Traumatic shock	*Date of diagnosis*	316	Rel. with autism					
Powerful shock	In this room, I was sitting here	318	Rel. with autism					
Devastating blow	When I had the news	322	Rel. with autism					
Devastating blow	When I received the news	324	Rel. with autism					
Shock - loss of function	I had nervous breakdown in this room	324-5	Rel. with autism					
Extreme loss	I was crying loudly and I couldn't control myself	327	Rel. with autism					
Trauma	My life completely changed	330	Rel. with autism					
Loss of control	*MER - I felt I needed to contain*	333	Rel. with me					
Trauma	I received a diagnosis of autism	360	Rel. with autism					
Need for containment	*MER - I remind of the boundary*	384	Rel. with me					

Having completed this process, I listed all the theme clusters for that participant in a Word document and began to look for patterns as to how they might relate to one another and form sub-ordinate themes. I used the columns *contexurisation*, *numeration*, *polarisation/links* and *function* as a guide (Smith *et al*., 2009). The groups began to form, along with possible names for the final sub-ordinate themes, as shown in figure 15. After this stage, I put the analysis to one side and moved on to analysis B and C for the next participant, bracketing off the previous experience in order to immerse myself in the next participant's data.

Figure 15: Development of sub-ordinate themes - family 3

Loss	
Deathly	extreme, deathly, severe, enduring, not able to see, stuck, repeating, depression,
Shock	
Life changing shock	shock, trauma, life changing, CT – shock, diagnosis, breakdown, overwhelm, in the moment, devastating blow
Unsteady foundations	relationship with me, unsteady foundations, nothing solid, indescribable, can you understand? Unbelievable, fragile, confusion, lack of meaning,
Unwanted feelings	
Punishing critical voice	hate for autism/child, useless daughter, critical about endings, relationship with diagnosis, rejecting, anger, frustration, diagnosis as punishment,
Humiliating exposure	humiliation, exposure, feeling judged
Relationship with loss	
Avoiding loss	avoiding endings
Pull towards loss	central nature of loss, focus on ending
Relationship with self	
Guilt	Guilt for hate, devastation, being rejecting
Desire for help	
Desire for help	desire for connection, eager, life, engagement
Therapeutic gains	
Establishing foundations	slow steady progress, broadening minds, overcoming, emerging, holding on, interviewer as link, slow recovery, lessening pain, recognised need, bringing in change, building on foundations, useful help, communication
Understanding beyond words	being welcomed in, linking up, being able to see for myself, understanding, working together, communication, advice as link, understanding beyond words, meaning
Life giving help	crucial help, crucial relationship, MER – rescue, fundamental change, drip feeding
Hopeful gratitude	Joy, relief, gratitude, expanded relationships-bringing in third, hope

3.3.7 Analysis D

Analysis D involves bringing the sub-ordinate themes together across the participants and developing a structure to illustrate the relationship between the themes.

As I considered analysis C for each participant, I noticed that the number of theme clusters for each family had become progressively fewer as I moved from family 1 to family 3. I felt this was mainly due to developing confidence in my analytic process. As I began to prioritise and reduce the sub-ordinate themes, I saw how some of the theme clusters in family 1 were more suited to coming together, and a similar process allowed for a separating out in family 3. This process felt useful for theme development but also seemed to mitigate my lack of analytic fluency at the beginning of the process.

I found three super-ordinate themes which had significance for all three families. I created a table with supporting quotes from the texts for each theme (see appendix G). I was aware that whilst the quotes are illuminating and necessary to illustrate the direct link to the data, in my application of the IPA method they are only one part of the evidence supporting each theme. The validity and depth of each theme is more apparent when supported with the other sources of evidence not visible in a single written quote (e.g. delivery, repeated words and phrases, the emotional communications).

I used supervision to check credibility and coherence for the themes. I also presented my themes in a PowerPoint presentation at the regional IPA group for peer comment. This process helped me to develop the names for the themes which the group felt needed to communicate more.

The final super-ordinate themes will be presented and discussed in detail in chapter 5, research findings. I found that the writing up process was in itself part of the analytic process: “as one begins to write up a particular theme, one’s interpretation of it can develop” (Smith *et al*., 2009 p198). In this way the themes were expanded and translated into a narrative.

Conclusions

I worked on analysing the data over a period of five months. It was extremely time intensive and at times confusing, but ultimately creative and enjoyable. I felt that IPA was an appropriate method to help the researcher “to understand the innermost deliberation of the ‘lived experiences’ of research participants” (Alase, 2018 p9). I will return to IPA as a research method in the concluding chapter of the thesis.

Chapter 4 Research ethics

Introduction

I will begin this chapter by outlining the formal process for obtaining ethical consent to carry out the research. I will describe the ethical dilemmas that were considered within the research design.

The remainder of the chapter focuses on ethical issues that occurred during the research process, in particular elaborating on patient distress and a consideration of defended participants in research.

4.1 Formal ethics process

As the research project involved NHS patients, I began the process for NHS ethical approval in January 2017 by submitting an Integrated Research Application System (IRAS) form for proportional review. This process focused my attention on the ethical issues inherent in the research design: ensuring confidentiality for the participants; informed consent; minimising risks for the participants/researcher and data security. I received ethical approval from the Research Ethics Committee (REC) in March 2017 and Health Research Authority (HRA) in April 2017 (See appendices H and I).

4.1.1 Confidentiality

In order to preserve participant confidentiality, I used alternative names for the parents, children and clinicians. Where possible, any other identifying details were omitted. I have not included full transcripts to further protect anonymity.

The eligible cohort of participants was identified by my supervisor, a clinician in the NHS clinic where the research was based and a member of the direct care team. In this way, I did not have access to patient identifiable information before consent was received.

4.1.2 Informed consent

Individual consent from each parent and psychotherapist involved in each case in the eligible cohort was sought. Consent aimed to give the participants adequate information about the research, its purpose and nature, any benefits and the burden to themselves. This information was outlined in the Participant Information Sheet (PIS) which all participants read before they signed the separate Consent Form (see appendices A and B). The PIS explained that a member of the team would contact the parents about the research. This was a member of staff at the clinic that the family did not already know in order to avoid any feeling of obligation to participate. A consent meeting was offered to give parents the opportunity to ask questions and discuss any concerns. The PIS also stated that the parents' decision about involvement in the work would not affect any future work or their relationship with the clinic. All of the parent participants who agreed to be part of the study were happy to be contacted by the researcher and did not wish to have a consent meeting before the interview.

No deception was involved in the study. The participants were encouraged to ask questions throughout the research process. All participants were informed that they have the right to withdraw at any time and this would not affect the care they receive. Participants' capacity to consent was assessed by the research supervisor.

4.1.3 Minimising risks

Parent participant

Potential distress during the parent interview, although not anticipated, was considered in the formal ethics process. We proposed that the researcher, a containing therapist, skilled at discussion with parents and well experienced in working with distress, would step out of role if required to prioritise patients' needs.

Researcher

One participant chose to have the interview in their own home. This was arranged within work hours and I informed the clinic of my arrival and departure at the participant's address in order to abide by the UEL working alone policy (see appendix J).

4.1.4 Data security

The data gathered for this research was stored in a locked cabinet in the researcher's home. Information stored on the computer such as audio recordings and transcripts were encrypted and password protected. The audio recordings will be deleted following the examination of the thesis.

4.2 Ethics in practice

4.2.1 Informed consent in practice

Through the process of informed consent, the participants were all aware that I planned to interview the clinicians involved in their cases as well and look at termly summaries/letters (although in practice, I did not examine this written data). Two of the participants referred in some way to the fact that I would see or hear information about them which they had not chosen to tell me themselves (see Discussion chapter, p135). In spite of some complex feelings that were communicated about this (such as feelings of exposure), the participants still wished to be part of the study. This could be viewed as evidence of informed consent.

As the parent participants had all received parent work (to varying degrees) and attended review meetings with their child's psychotherapist, they had experience of psychoanalytic thinking. These experiences arguably gave them some idea of what the research interview might involve along with the kind of thinking that would be applied to the data. This is not the case in all studies. As Hollway and Jefferson explained, "We felt that it was impossible to inform participants in advance, in ways that would be meaningful, about the experience of our kind of interviews" (2013, p80). In this study, the participants' experience appeared to inform their decisions about consent. I identified a degree of trust in the process, as can be seen in the issue of confidentiality discussed above. Indeed, during the clinician interviews, the therapists treated information about the families in the same considered, respectful way as they would in the clinical setting, communicating only what was necessary to aid understanding.

4.2.2 Patient distress in practice

During one of the interviews, a parent did communicate considerable distress as she spoke about the trauma of her child's diagnosis. After sometime, I became aware of her becoming stuck in her feelings and recognised a need for help. It was necessary for me to use some clinical skill in this moment in order to prioritise patient care, whilst also staying aware of the boundaries around my role, supported by the knowledge that our interview would immediately be followed by a session for the parent with the parent worker.

Hollway and Jefferson (2013) considered the issue of distress in qualitative research in some depth, tackling the idea that research should involve "no harm to participants" (p92). They argued that "distress" and "harm" should not be conflated, explaining their view that distress cannot realistically be avoided "when researching anxiety provoking subjects" (*ibid.*, p92). Hollway and Jefferson raised the question "is it necessarily harmful to experience being upset or distressed?" (*ibid.*, p80) They took the position that such an experience could be both reassuring and therapeutic if it occurred in a safe space within a relationship that involved quality attention (particularly to emotional content), containment and a lack of judgement. Such qualities would be found in a counselling relationship, but there also effective in producing the kind of data needed for this kind of research; "information which goes beyond rationalisation and opinion, which conveys emotional significance and does not avoid potentially distressing issues" (*ibid.*, p81).

I will consider the child psychotherapy researcher further in the concluding chapter of this thesis. However, it is helpful to note here that the participant in question communicated a desire to meet again and talk further towards the end of our interview, which although needed to be considered within the context of her relationship with endings, also seem to contain a feeling that the meeting had been experienced as helpful.

4.2.3 Defended subjects

Hollway and Jefferson (2013) also considered the issue of harm to participants when collecting data and writing about participants whose defences are firmly in place. This question concerned me during my analytic process as I wondered about the ethics of how the participants might interact with the themes which emerged. I thought about the usefulness of participants coming face-to-face with such thoughts about their internal world. I resolved to bracket off this concern as I carried out the analysis, so that as much as possible it did not interfere with the analytic process.

Krause and Cooper (2019) discussed the option of taking hypotheses back to the research subjects (participant validation). I gave this idea some thought and discussed it in supervision. As Hollway and Jefferson said, "Whether it is meaningful, or in a single participant's interest, to show him or her an analysis based on his or her single case is debatable" (2013, p84). They described how defences protect us all from "potentially distressing 'truths' about ourselves" (p90). An understanding of defences would lead to an expectation of disagreement over interpretation. In addition, I had not built this possibility into my study design and as such the participants had not consented to this level of involvement. I concluded that, in this particular study, such work should belong to clinical parent sessions and could not helpfully be included in research feedback.

Hollway and Jefferson explained that this kind of research is not about creating "truths" about a person, rather, "an account which is methodologically, empirically and theoretically convincing" (2013, p90). They described how researchers deceive themselves if they choose not pay attention to transference/countertransference in the relationship and instead take the participants' data only at face value. They cautioned researchers "to take the analysis only as far as evidence permits" (*ibid.).* They argued for a new ethics to meet their new research strategy which aimed to look beyond the surface, proposing that, for research to be ethical, it should involve feeling with the research participant and include a prediction of no greater harm "than that to which they have anyway been exposed" (*ibid.,* p86).

In my formal feedback to participants, I kept in mind the need to respect the participants' choice about how much they might want to know. I wrote a brief summary whilst also reminding them that the thesis would be published should they wish to explore the study further.

Conclusions

Hollway and Jefferson propose that the basis for an ethical research relationship is to "pursue the values of honesty, sympathy and respect" (2013, p92). I found this particularly helpful to keep in mind when considering ethical decisions throughout the study, keeping my focus firmly on the evidence, engaging with feelings of the participants, and showing respect through careful, close attention.

Chapter 5 Research findings

Introduction

In this chapter, after an initial section outlining the research context, I will present the findings of the IPA analysis.

5.1 Research context

Clinic Setting

There is an ethical dilemma in describing the research setting as it is unique and would become identifiable if I describe it in detail. For this reason I will restrict this description to a specialist multidisciplinary CAMHS service.

Interview settings

In order to facilitate ease of interviews for participants, I offered a choice of locations for the interview to take place. Each participant chose a different location (figure 16).

Figure 16: Interview locations

Participant	Interview setting
Family 1	Neutral clinic
Family 2	Home of participant
Family 3	Treatment clinic

As will become apparent in the data, the interview setting has significance, particularly for families 2 and 3. Family 1 chose to meet with me in a neutral place, an NHS clinic which was convenient to her place of work, not where the psychotherapy treatment took place for her family. Family 2 requested that the interview should take place in their home. Family 3 opted to meet in the clinic where they received the psychotherapy treatment.

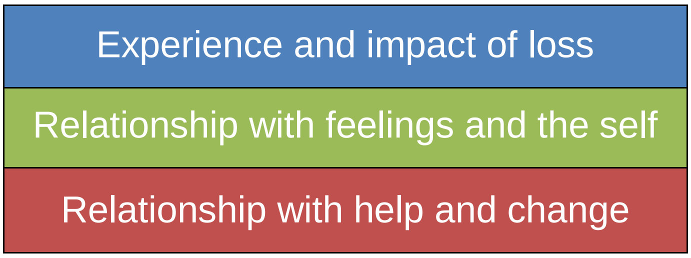
Following the interviews, I considered in supervision whether the variety and subsequent impact of the settings would prove to be a challenge for the research and we wondered whether themes across cases would emerge in spite of the different settings. Post analysis, I have come to feel that the participants’ choice of setting has meaning and deepens the understanding of the data. Links can be made to the themes which emerged and will be discussed as they are presented and explored.

5.2 Super-ordinate and sub-ordinate themes

I will now introduce three super-ordinate themes which emerged from the analysis with a brief summary of the sub-ordinate themes which sit under each super-ordinate theme. I will then present each family in turn, evidencing the significance of the themes for each case. I will conclude this section with a table showing the relationship between themes and across families.

5.2.1 Super-ordinate themes

Figure 17: Super-ordinate themes



Experience and impact of loss

“just get on and deal with the child you’ve got”

Central to this theme is the participant’s response to the child’s difficulties, the impact of the diagnosis and the loss of the typical child. Losses which relate to the child’s condition sit within the context of other losses the parent has experienced in life and their responses to these. For this reason, data connected to loss in general is included in this theme.

Relationship with feelings and the self

"but of course I understand her condition"

This theme developed from data relating to the participants' relationship with painful and difficult feelings; the position they take to such feelings inside themselves. It also includes the parent's response to their own capacities and limitations.

Relationship with help and change

"I kind of (pause) was happy for it to be a little bit (pause) murky"

This theme emerged out of how the parents experience and relate to help. Data concerned with the participants' relationship with and experience of any progress in their child is included.

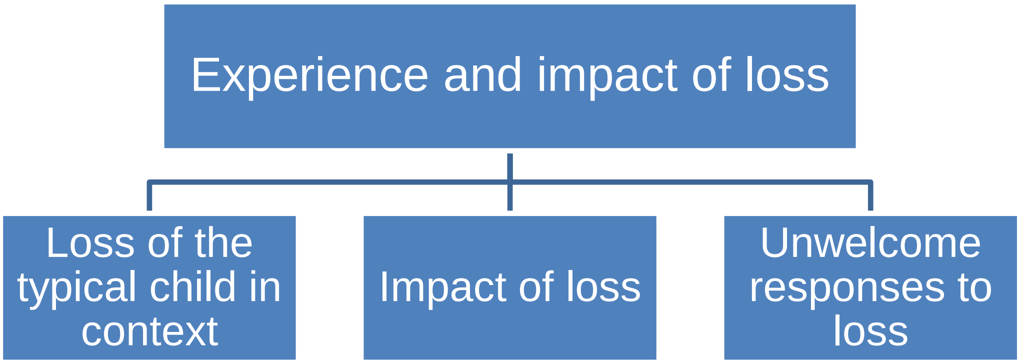
5.2.2 Sub-ordinate themes

Under each super-ordinate theme sits a group of sub-ordinate themes. Figure 18 shows the relationship between the super-ordinate themes its sub-ordinate themes. I will present an overview of the data clustered around each group of sub-ordinate themes in turn. Themes are colour-coded to aid reading. See figures 19, 20 and 21.

Figure 18: Super-ordinate and sub-ordinate themes

Super-ordinate theme	*Sub-ordinate themes*
Experience and impact of loss	Loss of the typical child in context Impact of loss Unwelcome responses to loss
Relationship with feelings and the self	Relationship with painful feelings Relationship with personal capacities
Relationship with help and change	Exposed and excluded Desire for help Therapeutic gains

Figure 19: Experience and impact of loss



Loss of the typical child in context

- Experiences of loss including
- loss of the typical child - symptoms and diagnosis
- loss of hope
- loss experienced as something deathly
- bereavements
- ending of the intervention

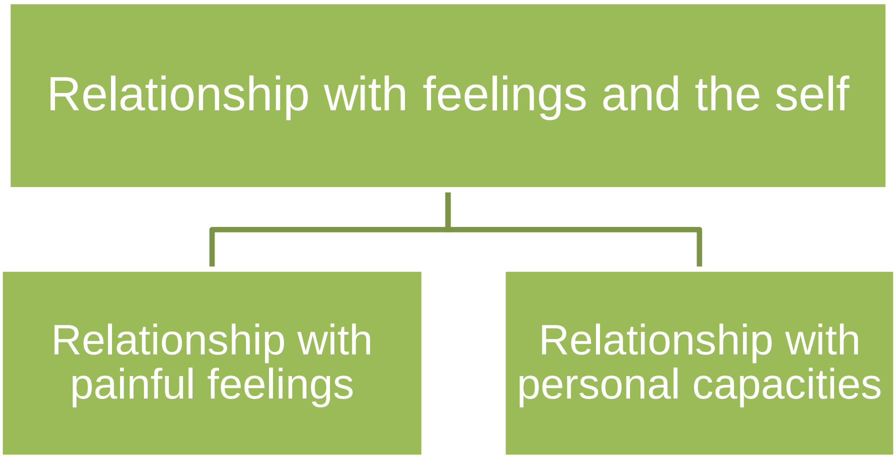
Impact of loss

- The impact of loss experiences
- shock
- disbelief
- unsteady foundations
- fragility/vulnerability
- crazy overwhelm

Unwelcome responses to loss

- Includes feelings which are hard to acknowledge towards a vulnerable child
- anger and hatred
- exposing/humiliating
- punishing/critical voice

Figure 20: Relationship with feelings and the self



Relationship with painful feelings

The participant's engagement with painful feelings including

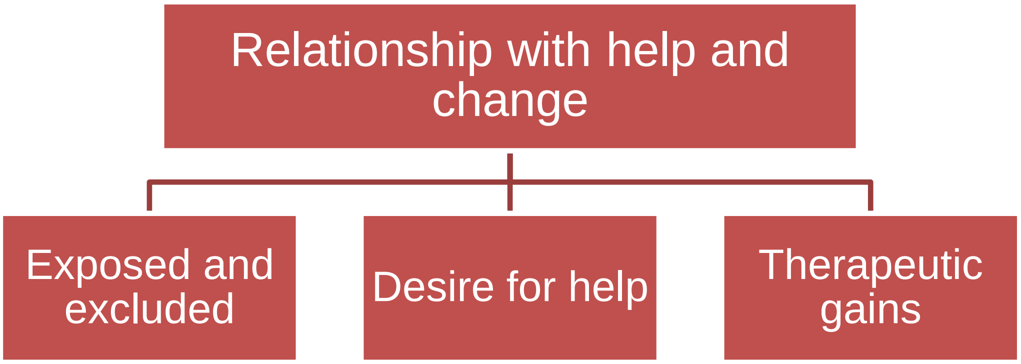
- distancing
- pull towards loss
- confusion
- self-reliance
- avoiding knowledge or desire

Relationship with personal capacities

Relationship with their own capacities and limitations including

- guilt/self-criticism
- fear of causing damage

Figure 21: Relationship with help and change



Excluded and exposed

Experiences of the intervention

- exclusion and exposure
- disbelief/scepticism/ambivalence
- judgement and criticism
- demanding/disappointing other

Desire for help

- Relationship with help
- overcoming
- anger with connecting

Therapeutic gains

- gains communicated as a result of the intervention
- development of understanding
- crucial importance of help
- establishing foundations
- relief/gratitude/joy
- hopeful wonderings
- life-giving help

5.3 Theme presentation by family

I will now illustrate in detail the relevance the themes for each participant in the study. As the research involved a small sample of three participants, I have chosen an idiographic presentation of themes where the participant is prioritised and themes for each person presented as themes within a case (Smith *et al.,* 2009 p109). I made this decision following a presentation to a regional IPA study group in which I presented my analysis thematically, taking each theme in turn and using evidence from each participant to support the theme. I found this presentation method was more difficult to follow. I reverted to an idiographic presentation in order to preserve the internal cohesion of the account. Following this I will present a table of themes which draws the themes together across cases.

Through the process of analysis, it became apparent that, although each of the super-ordinate themes was present in the data of each participant, one of the themes had a particular relevance and was dominant for each family. I will describe the significance of the dominant theme as I present each participant.

I will illustrate the themes through extracts from the participant’s transcripts, pointing out the sources of evidence to support the theme. The extracts chosen are at times necessarily long in order to reveal the nuance within them. As such they are complex passages which usually contain examples of more than one theme. To aid clarity, I will focus on the theme in question and make reference to the extract again when presenting later themes. I have included line numbers from the transcript in order to give an indication of where the passage occurred in the interview. Theme clusters, sub-ordinate themes and super-ordinate themes are all referred to in italics.

5.3.1 Family 1

Family 1 includes participant Christine, her husband (name not mentioned), eldest son Austin, who has an autistic diagnosis, and two younger children. Austin was six when the treatment began. He received intensive psychotherapy for one year, eight months. Mary is the therapist and Lisa the parent worker. The work concluded one year four months before the interview took place. Figure 22 provides an overview of themes for this family.

Figure 22: Table of themes – family 1

Family 1								
Super-ordinate theme	***Experience and impact of loss***			***Relationship with feelings and the self***		***Relationship with help and change***		
Sub-ordinate theme	***Loss of the typical child in context***	***Impact of loss***	***Unwelcome responses to loss***	***Relationship with feelings***	***Relationship with personal capacities***	***Exposed and excluded***	***Desire for help***	***Therapeutic gains***
Theme clusters for this family	***Loss***	***Shock and disbelief***	***Hatred/ anger***	***Engagement with pain***	***Guilt***	***Exposure***	***Overcoming***	***Linked up understanding***
		Ungrounded		***Murky confusion***		***Feeling excluded***		***Crucial importance of help/ experience***
						Disbelief/ scepticism/ ambivalence		***Relief/ gratitude/ joy***

Family 1 – Experience and impact of Loss

Loss of the typical child in context

For this participant, theme clusters emerged that were concerned with feelings about the *loss of the typical child* through his autistic presentation. Powerful feelings of loss were also communicated about the ending of the therapy.

In the following extract, Christine describes feelings about her relationship with Austin before the intervention began.

> Quote 1
>
> because it's, it's so easy when you have a, with a normal child, normal, you know, neurotypical child, erm you, (pause) they, they are conven..., they, they interact conventionally with, you know, with their teachers and with adults and, you know, (inhale) erm people. I always felt with Austin that he was behind this kind of wall of kind of very opaque glass, you know, and I knew, you know, I knew him, I knew, I kind of understood him but his communication was so poor and, and indirect that it really sort of took some, you know, quite a skilled person to, to, to, to get through to him (line 140).

The image of her son behind a wall of opaque glass communicates a painful loss of "normal" interaction; an idea of a child out of reach and beyond her skill (see later themes of *guilt* and *gratitude*). Christine describes a typical child's interaction with "their teachers and with adults ... and, you know, (inhale) and erm people" appearing to avoid any mention of herself, which to my mind in this moment felt too sensitive a loss to connect to or communicate explicitly (*exposure*), which she overcomes following her intake of breath (see later theme, *overcoming*).

Alongside the content of the extract and choice of language, I considered that the *loss of the typical child* was communicated through her lack of fluency and repeated "you know", which appeared to contain an element of, "can you know?" With this participant, I was struck throughout the interview how moments of emotional pain were accompanied by a lack of fluent delivery. It seemed that she was struggling to communicate something which was painful to connect to (*engagement with pain/exposure*) and hard to imagine could be understood (*disbelief/scepticism/ambivalence*).

Powerful feelings of loss were also communicated when Christine spoke about the loss of the intervention. In this case, the family had to move away which brought about the ending of psychotherapy which in Christine's view was premature and regrettable.

> Quote 2
>
> and, erm, but we were, we stayed, we stayed in London for as long as we could so that he could go to this school and also so he could do psychotherapy but, um, it was, er, I had another baby, my husband was training to be a doctor, we were, it was crucifying us financially, erm, and in the end we had to leave, we really had to but we agonised (stressed) over the decision literally, probably from the moment that I met Lisa until the day we left. It was, the day that we left was appalling, (pause) um. So I think there was a lot of anxiety arou .. surrounding the end, um (pause) (line 216).

Particularly illuminating here was the choice of language, "crucifying ... agonised ... appalling". The strength of these words, which could be considered to link to religious imagery, made me feel that Christine really wanted me to understand the enormity of the loss, perhaps with some sense that I might not. Later in the interview, she returned to talking about the move.

> Quote 3
>
> it was such a big change for him, so we moved from central (*city location*), you know busy, very vibrant wonderful school, erm, with lots and lots of support, psychotherapy and music therapy and everything that we possibly could get for him, erm, to moving to the countryside were there was nothing, you know, there was, there was, no, there's been no services at all (laugh) and to a school that really didn't understand him (line 424).

Here I thought about the loss of all the support she experienced in the house move. There was a feeling of being bereft, a move from "vibrant" life, to "nothing". The laugh seemed to offer a relief from a powerful and perhaps disturbing feeling. As will be discussed later, Christine repeatedly spoke about the development of understanding as a significant *therapeutic gain* from the work. I felt that the final comment about "a school that really didn't understand him" contained a reference to the significance of loss of the intervention brought about by the move.

Impact of loss

> Quote 4
>
> he'd done his reception year, with pretty, was pretty smooth, we were pleased with his, his transition into school, but there were a few issues that, um, we were, we were worrying about. Um, his, he was sleeping very badly (cough,

> cough) and he was eating very badly too. So, erm, I think I was attending an eating clinic um and during that um session, one of the session, err, there was a clinical psychologist there and I was telling her about his, his sleep, um, and at the time, he was, um, (pause) he (pause) we'd wake up in the morning and he'd (force) chewed his bed. I mean, he'd sort of been gnawing through the wood on his bed (line 22).

This extract is from early on in the interview. Again, Christine's delivery felt an important component in communicating the impact of the loss; the level of the impairment in her son. There is a cough and a lack of fluency in repeated uses of sounds like "um" and "erm" which in this context felt like a difficulty in knowing quite how to put it along with perhaps some resistance. This was the first description of anything unusual or disturbing about her son. I thought about her feelings of *exposure* in talking to a stranger about this.

In the interview and then in my repeated listening and reading, I noted my *shock* when Christine said the words "chewed his bed". I felt that I experienced a ripple of her *shock* at having a child with these kinds of difficulties. Her tone at this point also seemed to contain a feeling of *disbelief* in the level of his impairment.

Along with *shock and disbelief*, I noted in the content a description of basics, sleeping and eating, not being in place; a sense of something *ungrounded*. I had a similar feeling shortly before this passage as we began the interview when I realised I felt unclear as to whether Austin had a diagnosis of autism and the level of his impairment. I felt a powerful lack of solid foundations for the interview. In my analysis I saw a connection between my feelings in the room (REM) and the theme of something *ungrounded*. This is an example of how I used my emotional response to support other evidence in the data, adding an additional layer of substance to a theme.

Unwelcome responses to loss

Analysing Christine's data, feelings of *hatred/anger* became visible. In the following passage, Christine talks about Austin's reaction to the births of his two siblings.

> Quote 5
>
> he'd had a terrible reaction to my second child. Erm, bef.. that was before he was diagnosed, erm but I think we started to worry when he, when she came along. But he was, I mean he, he just loathed Georgie, it was awful. And, erm, tried, he was never violent but he just tried every (pause) you know, just to, to

> make it clear to us how much he really hated it, hated having a little boy, brother (line 263).

I thought about Christine’s feelings that were perhaps projected into Austin in this moment. There is a linguistic slip, where she uses the phrase, “hated having a little boy”, which would flow more naturally if she were talking about her own feelings, before correcting herself to “brother”. The choice of language is very strong “loathed ... awful ... violent ... hated ... hated”. This strength of feeling is perhaps also evident in the confusion within this passage. Christine speaks about her third child Georgie (a name which could apply to either gender) as “he”, then “she”, then a “boy/brother”. The confusion here (to be discussed under the next sub-ordinate theme, along with the projection, may allow distance from *unwelcome responses to loss*.

Family 1 – Relationship with feelings and the self

Relationship with painful feelings

This theme for Christine is concerned with data relating to *engagement with pain*, moving towards and away; being in touch with and then requiring distance. In the material already quoted, it’s possible to see distance from strong feelings in the delivery of quote 1 and the possible projection in quote 5 above. In the following passage, Christine was recalling the backdrop to the start of the psychotherapy treatment for Austin.

> Quote 6
>
> So I think that was the backdrop, yeah I remember, yeah so I, I had Georgie in at the end of reception and then he went into year one and that year we went to, we were going to psychotherapy. End of that year. So, (pause) and we also moved house that summer, so there was moving house, Oh God, (laugh) there was also, erm, so there was Georgie, moving house, and then we had this terrible accident in, when we were in France erm, where our (pause) we were driving back from France, we were driving to the ferry, Eurostar, tunnel, and erm, our car caught fire (R - goodness) and we, 50 miles from Calais our car caught fire and we pulled to the side of the road, flames in bonnet, so we had to get you know, we threw all of the children out, ran around to sort of, just behind a hill, so we didn’t actually see it happen but then the car exploded basically (laugh) which was obviously, you know incredibly traumatic for all of us (line 265).

This terrifying incident was initially forgotten about. Christine laughs when she realises that she's left it out of her account as if she cannot believe she forgot to mention something so significant. At this moment in the interview, I felt concern for this family with a very small baby and young children in such a situation and thought about feelings of terror and extreme vulnerability. Christine's laugh suggests that, whilst she is speaking, she has some distance from these disturbing feelings. I was struck by how she drew my attention to the fact that "we didn't actually see it happen", another mention of distance.

At other times, Christine communicated a connection to strong feelings, such as those evident in the following quote through the choice of language, "painful, difficult ... needed … needed".

> Quote 7
>
> I was having weekly sessions with Lisa (R - mmm) which I found incredibly helpful, incredibly sort of (pause) painful, difficult but, you know, I felt that, erm, (pause) it was kind of stuff that erm I needed to, I sort of needed (inhale) (line 117).

Along with *engagement with pain,* a linked theme of *murky confusion* emerged. This can be seen in quote 5 where confusion perhaps allows distance from something potentially overwhelming. This theme cluster shows itself in thoughts about the intervention itself. Christine spoke about Austin's sessions and how she didn't really know "what went on".

> Quote 8
>
> You know I completely trusted Lisa and therefore Mary because she was supervising Mary and a, you know I kind of (pause) was happy for it to be a little bit (pause) murky, erm (line 97).

The description of the psychotherapy as "murky", not clearly visible, made me wonder about the difficult feelings there may be towards the therapist's capacities, referred to in quote 1, "it really sort of took some, you know quite a skilled person to to to to get through to him" (line 148) and how the murkiness may provide some relief. I also wondered about a link to the child behind opaque glass (line 144), a picture of her son as also not clearly visible.

Relationship with personal capacities

It is possible to trace through the data feelings of *guilt* about personal capacities, needs and limitations as well as necessary family decisions (quotes 1, 2, 3 and 5). In the following extract, Christine talks about her lack of understanding about the nature of her child's difficulties before the intervention.

> Quote 9
>
> His main problem is anxiety, it's which is a, which is a result of the world being (pause) not his world really, and so, and so everything is terrifying and everything is overwhelming but he (pause), so I, I, but I didn't really understand the nature of anxiety in an autistic child, I think, or I didn't understand that anxiety was the main issue. I just thought he can't really speak properly and that's, that's why he can't eat properly and that's why he can't, um, sleep and why then he's so confused (line 174).

Feelings of self-criticism and *guilt* were evident to me through the content of this passage, but also her delivery, tone of voice, and my associations in the moment as she spoke.

My awareness of self-critical feelings was supported by my emotional response at moments in the interview. In the extract below, Christine had just spoken about how Austin's anxiety levels improved over the course of treatment and about her growth in understanding about how he might feel when he woke up in the morning. There was a pause and I prompted;

> Quote 10
>
> R I wonder about school … about how he was in school at the time ...
>
> C hmmm. As I said at the beginning, he was very withdrawn and he, he was never, he's never been any trouble at school (line 354).

At this moment, I perceived some annoyance in Christine's tone (delivery) which is not evident in the transcript alone. She had already told me this information and perhaps experienced me as not listening attentively enough, rather than hearing my wish for her to expand on her reflections. I felt self-critical that I had been clumsy with my prompt. I thought about the presence of self-critical feelings, alongside feelings of *gratitude*, about needing professional support in order to help her son.

Family 1 – Relationship with help and change

For Christine, this super-ordinate theme is the most dominant. The three sub-ordinate themes are all concerned with the participant's relationship to the intervention.

Exposed and excluded

Previous extracts can be seen to show uncomfortable feelings of *exposure*, such as in quote 4 when Christine pauses and stumbles before she first talks about her son's bizarre behaviour to a stranger. Exposed feelings can also be seen in reflections about the intervention itself. I thought about how it feels for a perhaps private family to have their life so visible to professionals, particularly when considering the feelings of *guilt* and self-criticism discussed above. Content and delivery (laugh) illustrate the point in this quote about Austin's play in his sessions.

> Quote 11
>
> all his play had, involved family members so, you know there were (laugh) family members who had different names but they were quite obvious who they were, um (line 335).

In the following, longer extract, I identified a struggle with *feeling excluded* from the relationship between her son and his therapist, alongside other feelings of *relief* and *gratitude*. This is evident through the content, delivery and language of her initial question to Austin about what goes on in the sessions, which seemed to contain a sense of "What do you like there, where I am not?"

> Quote 12
>
> I think I said to him "what do you play when you're in the sessions, or do you like your play?" And he said something like "I go and I and I play and I talk", and he kind of looked at me like, you know I talk, as well. And I thought that was amazing because he really, you know, that's, a) that's not the kind of thing he would ever have said (R-mmm), erm, but also it showed this understanding that it wasn't, it wasn't just about play. Because he, he had done you know many, many sessions of this that and the other and, you know, speech therapy and, you know, he'd had, he was very used to the kind of one-to-one situation but I think, you know, this felt for him more than that. (R – hmmm)
>
> Erm, (pause) and we (pause) so he, I think he made quite a strong bond with Mary pretty quickly and they, they seemed very pleased that he was, erm,

> (pause) that he was, erm, receptive to psychotherapy. I mean I still don't know what went on really (laugh) I have no (pause). You know I used to ask in my sessions with Lisa um, what had come up and, and we, we talked a little bit about that but not, not a huge amount, um, and, you know, I've never, I've never seen any reports (pause). We had, we had kind of reports that they wrote for the annual, annual review and we had catch-up meetings, but we didn't have kind of, you know, formal feedback like you would normally have with, um, therapists. Um, but I was com..., very comfortable with that (line 63).

Following her thoughts about the significance of the work for her son where Christine differentiates between psychotherapy and other kinds of interventions, she talks about the bond he made with the therapist with some distance, describing how "**they** seemed very pleased", rather than herself. After the laugh, her voice became stronger. Here I felt was a strong feeling about how it was to be in the dark. I recalled in the moment trying to meet this feeling and communicate understanding though my facial expression as she spoke. I discerned some *ambivalence* in her final statement about being "very comfortable"; this moment seemed to contain something of the trust she felt in the therapists alongside her feelings of exclusion.

Ambivalence was particularly evident in the interview data and is central to the next theme cluster. *Disbelief/scepticism/ambivalence* had an incidence of 32 (numeration) which was a high figure for this participant.

> Quote 13
>
> But (pause) he, he, he seemed to make progress very quickly and um, (pause) I mean it, it was, it was, it's very hard to say whether, of course it's very hard to say whether it was the result of the psychotherapy or it was something else but, um (line 106).

Christine repeatedly stressed the difficulty in knowing exactly what made the difference for her son, alongside comments about just how crucially important the intervention had been for all of them. Sometimes she was connected to sceptical feelings, "I think I was very sceptical" (line 191), and at other times the feelings appeared to be projected into someone else such as her husband or another parent as in this passage.

> Quote 14
>
> Somebody at Austin's school, who was also in the autism resource base, (pause) erm had had psychotherapy and it had been very successful and she was somebody who, the mother err, was somebody who is very kind of

> straight down the line, kind of belt and braces, you know, really, I, I wouldn’t have thought it would be something that she would have gone for (line 34).

I wondered about the role scepticism might play in providing distance from feelings of *exposure*, *feeling excluded* and *guilt* mentioned above.

> Quote 15
>
> I obviously know parents at the school where we used to be who have also had psychotherapy but had less intensive and I think possibly themselves are less kind of receptive to it or (pause) erm, have found it not perhaps, not as life-changing as we found it and kind of as satisfy (cut short-pause) satisfactory but anyway (line 556).

In this quote, Christine describes the psychotherapy as life-changing. Then the word “satisfy” is dropped and becomes “satisfactory” which I felt had a much more perfunctory feeling than the life-changing description a moment before.

I also wondered about an idea of *disbelief* in any help, evident in quote 1 where I had a sense of, “can you understand?” Could anyone really understand or help? The following quote continues on from quote 4.

> Quote 16
>
> I mean, he’d sort of been gnawing through the wood on his bed. And um, he was waking up and becoming very distressed very quickly. Um, and she said, you know, she suggested that, well you know, perhaps there was something that someone could do (small laugh) (line 31).

She laughs at herself perhaps in recognition that she had not considered that there might be help out there.

Desire for help

A theme of *overcoming* developed from analysis which felt central for this participant. The theme includes a desire or capacity to move beyond feelings of *scepticism* or *exposure* and form a strong commitment to the work. This sense of *overcoming* came across most strikingly in Christine’s delivery. At times when she was communicating a painful or sceptical feeling, there was often a pause or breath and then a surge forward in the way she spoke, with greater fluency and sometimes volume (see quotes 1 and 4). In this passage, which is a continuation of quote 7, I felt Christine was in touch with how painful but necessary she found the parent work, she stumbled and struggled to find the words, but following her inhale, she spoke with greater fluency about the insight she felt her parent worker had about her child and how crucially important this was to her.

> Quote 17
>
> I was having weekly sessions with Lisa (R – mmm) er, which I found incredibly, incredibly sort of (pause) painful, difficult but, you know, I felt that, erm, (pause), it was kind of stuff that erm, I needed to, I sort of needed (inhale, pause, then much faster) with her knowledge of Austin, and I felt she really did have a knowledge of Austin even though she'd not met him many times, I felt that she, she'd done the assessments and she'd obviously talked to Mary a lot, lot, and I felt like she, she had a real insight into him, which lots of people claim to have when you, when they, when you have an autistic child, they're, they're dealing with lots of professionals (R-mmm) and you know there's, there's lots of goodwill and there's lots of involvement but there's only a few people I think that really kind of get it and try, and really try to get him, and I really, really (stressed) felt that she did and I think when you're a parent of a special needs child, that's what you want (line 117).

Later in the interview she spoke about her commitment to the parent work. She described the value of the sessions for herself and related this to her son and the benefits he might be getting from his therapy (*linked-up understanding*).

> Quote 18
>
> I was very involved in that psychotherapy and, I, we, we had it, you know, it was supposed to be family, but it was really for me, erm, and so I understand what was, what I took from it (pause) whereas I, and I couldn't put my finger on, I couldn't explain to somebody else what that necessarily was, it, but we were talking about, if you're thinking about Austin, of course he's not going to go to tell me what he does or, you know, what, what the kind of nuts and bolts are, erm, I think I just have to trust that, that, that, that he is, from the evidence, that he seems happier and, you know, that, that there is something going on, do you see what I mean? That only he, only he knows what he got from his psychotherapy in the way that only I know what I got (line 503).

Therapeutic gains

Under the sub-ordinate theme *therapeutic gains,* theme clusters emerged around *linked-up understanding*, *the crucial nature of the help* and *relief/ gratitude/joy.* The idea of links and developing understanding came through many times in the data. This theme cluster had the largest numeration for this participant – 51. The theme is illustrated above in quote 18. Christine went on to say more about the value of the parent work.

> Quote 19
>
> I felt that it was incredibly important (stressed) what I was doing with Lisa and I, and I really, and, and it gave me a huge (stressed) insight into myself that I, you know I'd never sort of had before (line 524).

She made a link to the significance of the sessions for her son. In the following quote she describes the lack of a link before the psychotherapy began.

> Quote 20
>
> I couldn't really understand how it would help, it could lead to him being um more communicative and more um and happier. I didn't really, I didn't understand the link. Um, whereas I think what we, we have discovered (pause) through psychotherapy is that erm he (pause) his main problem is anxiety (line 164).

The linking-up is evident in the use of "we"; an implied learning together, whether she is referring to her and her husband or the therapists.

There were themes of desperation before the intervention began, where Christine was "ready to give anything a go" (line 195) and a stress on the crucial nature of the help they received through the intervention, particularly a development of understanding, both of herself (quote 19) and of her child's difficulties.

> Quote 21
>
> It's not to say he was mute but he, he, he didn't, you know, he never asked for anything and, you know, he never said he was hungry, he never said he was cold, he hurt himself or anything, you know, you know, it was just, he just seemed to be this total, you know, loner who just didn't have those feelings (pause)
>
> And, you know, I just thought he, he didn't have those feelings. And the, the, kind of massive revelation to me, going through psychotherapy and coming out the other end was actually, (laugh) you know, instead of him not having any of those feelings, he had those feelings but in absolute spades, erm, so I think his, so his language needed to catch up with, with what was going on inside and, um, it didn't, I mean it didn't, kind of didn't happen immediately but erm, but, um, but (pause) he would suddenly say something, and, and we'd just, oh my God, wow, that's an insight into his soul, you know, didn't think was, existed. I mean I really think that we felt we would never know him properly, we never, um, we'd never really know what was going on inside him, so I think we pretty much feel that we do now (line 393).

The choice of language “massive revelation” and “insight into his soul” could again perhaps be felt to have religious overtones (see quote 2), perhaps supporting evidence for the crucial nature of the help. Christine became more fluent as she spoke about this and seemed to want me to understand how enormous this gain had been for them as a family.

Following on from this, the final cluster of themes was around *relief/gratitude/joy*. *Gratitude* is evident in the above (quote 21). I noticed at this moment I also felt incredibly grateful to Christine for her willingness to engage in the interview and be so honest and open, MER providing additional evidence. I became aware of feelings of *gratitude* and *relief* in Christine occasionally in the interview when she was floundering a little and I asked a question or used a prompt. These feelings were communicated through her delivery and my associations.

The final quote illustrates a sense of *joy* in Austin which came through the data. This material follows a prompt from me asking more about the changes she had described in her son during the psychotherapy and how things had been since the psychotherapy ended.

> Quote 22
>
> you know, he’s, he’s, he’s amazing, he’s doing amazing things, um, so I think, and it, what he’s starting to do is, is, is as I was saying, he’s writing a lot, he just, very kind of, I think of it as being a very un-autistic thing to do. You know, he writes, he writes about big feelings and, erm, yeah I feel like that’s, that’s an amazing thing for him to be able to do, he, he totally sees himself as an emotional being interacting with the world on an emotional level (R-mmm) which is great. It’s also quite challenging (real laughter) (R-laugh) for us. But, you know, better that way than, than before when he, when he was just exploding and not expressing (line 455).

The alive laughter seemed to communicate joy in her and his “un-autistic” qualities in spite of the remaining challenges and difficulties.

I will now move onto the second family. Figure 23 illustrates the themes for this participant.

Figure 23: Table of themes – family 2

Family 2								
Super-ordinate theme	***Experience and impact of loss***			***Relationship with feelings and the self***		***Relationship with help and change***		
Sub-ordinate theme	***Loss of the typical child in context***	***Impact of loss***	***Unwelcome responses to loss***	***Relationship with feelings***	***Relationship with personal capacities***	***Exposed and excluded***	***Desire for help***	***Therapeutic gains***
Theme clusters for this family	***Loss***	***Crazy overwhelm***	***Theme not present***	***Distancing***	***Guilt***	***Excluded/rejected***	***Anger with connect-ing***	***Hopeful wonderings***
				Diminishing	***Fear of causing damage***	***Critical judgement***		
		Vulnerability		***Self reliance***		***Demanding disappointing other***		
				Avoiding knowledge and desire	***Personal capacities***			

5.3.2 Family 2

Family two is comprised of the participant, Beth, a single mother, her son James with autism and a younger son, Samuel. James's psychotherapy began when he was three years old and lasted for one year, seven months. The interview took place in the family home, three years, eight months after the end of the psychotherapy. James's therapist is called Kira. The parent worker's name is not mentioned.

Family 2 – Experience and impact of loss

Loss of the typical child in context

The theme of *loss* for this participant emerged from material relating to loss of the typical child, loss of Beth's own parents and loss of hope.

Beth communicated a pragmatic relationship with James's diagnosis of autism. Examples of *loss* in the data most often suggest a matter-of-fact response. For example, when speaking about non-verbal children with autism, Beth said, "some kids with autism will not speak, will have a few words, it's, it's just how it is" (line 629). In this moment there seemed to be an idea of a fact that needs to be accepted with little point in hope for development.

I saw a similar idea of loss as a fact to be accepted and not dwelt upon in the following extract. Beth is talking about James's psychotherapy sessions and her discussions with the therapist and parent worker. She describes how at one point,

> Quote 23
>
> they said he was mentioning something about a grandfather or they thought he might have been a bit upset about a relative who had died or whatever. I was like, no, I haven't had grandfathers, my dad died donkeys' years ago, you know and stuff like that, so sometimes they might come back and say, oh we were wondering if he was a bit concerned about whatever, I'm like, they're not, you know, parents died years ago, I've got loads of siblings and whatnot but erm, that, other than that there wasn't really anything kind of untoward that came out of it (line 579).

The tone of delivery was an important source of evidence here. To my ears Beth's tone in this moment was dismissive (*distancing*) as well as containing some annoyance at this, for her, incorrect and "untoward" suggestion that such losses were on her son's mind.

At other moments, Beth seemed to connect differently to feelings of *loss*. She described the diagnostic process for James and told me about a report written by the speech therapist when her son was very young. She described how the speech therapist had written

> Quote 24
>
> you know everything, you know, blah de blah, severely delayed d d d d, severely delayed. You know, it made for horrible reading (line 389).

Here her tone was reflective as she remembered this stark, “horrible” experience.

Impact of loss

In Beth’s data, a theme of *crazy overwhelm* began to emerge which felt significant.

> Quote 25
>
> so Samuel wasn’t even one because he was one in the October, so yeah, then it was pretty full on and yeah tough because he, he definitely had words then, he was speaking then but he was very, very unruly, at least, well he’s a bit mad now but you can at least talk to him, yeah it was (pause). In some ways he’s a sweet happy boy that, you know, he liked to spin, er, saucepan lids on the table there and, you know, look out the window and just flap and stuff like that so sometimes it was very hard getting through to him and other times it would be difficult going outside because he was just suddenly run across roads and whatever but, um (line 154).

My associations as well as use of language were used to provide evidence for this theme. Beth used words such as “unruly”, “mad” and “spin”, describing behaviour that was unpredictable and out of control. As she spoke, my thoughts went to just how much this mother had to manage at this time in her life. Later, she spoke of the many interventions James was having alongside his therapy. “Erm, so I was just going absolutely (pause) (R - yeah) full on with everything” (line 417). The phrase that came to my mind at this moment was “going absolutely ... mad”. Shortly after this, she spoke about the kinds of interventions people turn to in their desperation, describing “bonkers therapy” and “crazy stuff” (line 471). I thought about the experience of *overwhelm* and the self-protections needed in the face of something too much.

The idea of spinning out of control in an overwhelming fashion is also evident in the following extract. I had asked Beth if she could say a little more about how things were for her and the family when they started therapy.

> Quote 26
>
> I’m sure like a lot of people, very overwhelmed (pause), very nervous about what the future holds and that still kind of goes up, up and down in waves, depending on how it’s going at school or whatever. Just, just yeah, very, very uncertain and, and I keep banging on about the fact that I hadn’t had a job at the time as well but that, just everything. I had a little baby at the time and then I was just panic stricken about, is he gonna, would he be autistic as well and you know and, and, and also it’s like anything now, you read stuff on, on, you Google stuff and it always gives you the worst scenario, you know, you could Google that you’ve got a headache and a cold and it’s like suddenly you’ve got, according to that you’ve got cancer (line 269).

The imagery, “up and down in waves” implied a feeling of being tossed about, a lack of anything solid. Her move to the present felt significant. As Beth recalled that time in her life, the feelings seemed to become current ones. In her description, a minor problem becomes something devastating and life-threatening. I thought about the “little baby” feelings of extreme *vulnerability*, which developed into another theme cluster. In the following quote, again Beth used the present tense when she spoke about the stressful time she was having back then.

> Quote 27
>
> It’s really hard trying to remember things that went on at home because I did, so while the psychotherapy was going on, it was generally to be honest quite a stressful time at home I think because I’m job-hunting, so I’m worried about money, job-hunting, two kids which I, you’ve probably got it on your record somewhere that I had them on my own, so there is, it wasn’t like at the weekends that they went to go and see dad every other weekend or someone came round and stuff like that. So I think weekend wise I felt very alone (line 430).

Although distance from feelings of *vulnerability* (*distancing*, *self-reliance*) occurred frequently in the data, in this moment I felt Beth connected with how it was to feel “very alone”.

Unwelcome responses to loss

Strikingly there were no occurrences of this subtheme for this respondent. I will consider the significance of this in the discussion section.

Family 2 – Relationship with feelings and the self

This is the dominant super-ordinate theme for this participant.

Relationship with painful feelings

The themes which clustered around this sub-ordinate theme were: *distancing*, *diminishing*, *self reliance* and *avoiding knowledge and desire*.

In Beth's material, there were many examples of *distance* from painful or uncomfortable feelings (see quote 23) such as in data about forgetting, physically moving away, descriptions with large amounts of detail (staying away from – see quote 37) and through identifying feelings in other people.

Beth mentioned her struggle to remember in quote 27 (also see quotes 29, 31, 32, 36). Obviously, as the interview for this case happened at the longest distance from the treatment itself, it is unsurprising that much of the detail was hard to recall. However, the repeated instances of *distancing*, (numeration – 53) built up its validity as a theme which to my mind was something more than simply the passage of time. Describing her son, Beth told me, "but obviously he has autism which gets forgotten about" (line 110). Although she was referring to other people forgetting, in the context of other evidence, I wondered if she was communicating something about a way of managing potential overwhelm. In the following longer passage, Beth refers to her relationship with the parent sessions which she eventually stopped attending. Throughout the interview, she struggled to remember the name of the parent worker. Here, she describes how she did not want or need to talk about her son's condition, as her mind was "somewhere else" and she preferred to "check out of reality".

> Quote 28
>
> so I used to sometimes then go in to speak to (pause) it's really irritating me that I can't remember her name. I can really picture her, and then erm, for me I think because my mind was somewhere else, which was, I need a job (R – yeah) I got to the point where I, and also I think just being stressed out at home and having a little baby, I was ending up using the (pause). It suited me more to use the sessions just to sit in reception and I would either catch up on reading a book, because that's, that's like nice me-time isn't it. It's where you kind of check out of reality or whatever you want to call it. Or I'd be sitting there emailing, texting and, and actually (pause). So for me, that was more valuable to me rather than needing to sit and talk to someone, because I guess for me also with the autism it's just like, you know what – it happens.

> You get it. I don't think I did anything wrong in my pregnancy. He didn't catch it, you know it is what it is and there's far worse things that can happen. My poor very good Uni friend, her 19 year old daughter died on New Year's Eve, completely out of the blue. You know so I've got a kid with autism. So what. You know what I mean, so, so I wasn't looking for answers (R – hmmm) as to why or, or, or what about this (pause) You know, I, so I was just like, he's got it, we're dealing with it (line 594).

Here a devastating loss is described in her friend which may allow some distance from intense feelings.

The location of the interview, in the participant's home, I would argue provided a possibility to physically create distance that would not have been available so readily had the interview been in a clinic room. On a number of occasions, Beth excused herself and got up to do something else for a moment. This developed significance in the context of the many other ways in which *distancing* emerged as an important theme.

In the above Quote 28, the choice of language was striking when Beth described time alone as more valuable to her than the need to sit and talk. I understood a wish to have distance from need. In the following material, Beth spoke about her desire for *self-reliance*, without the need for others; a situation arguably necessitated by her life position as a single parent.

> Quote 29
>
> But I don't feel for me that I needed that support network of other autistic mothers, well they're not, you know parents of autistic children, I didn't necessarily feel I needed that, I felt I had enough on my plate as it was (pause) um, yeah, sorry I've gone off on a tangent again, I can't remember what we were saying, but, oh, yeah, I can't remember, I'm going blank (laugh) (line 254).

The cluster of material around *avoiding knowledge/desire* gained validity through numeration (incidence of 79). It can be seen in the above two quotes (28 and 29) which both describe a lack of need for the other, in the first case for the parent work, and in the second for a support network. Regarding feelings about the intervention generally, use of language was an important source of evidence. Here Beth describes how they came to be involved in psychotherapy. There are

Quote 30

> all sorts of people, you know services wanting money, so I think, if they had said, if, if (*named council*) has thought, right, yes, we think that's worthwhile, setting aside that, and the psychotherapists think it's worth it, I was happy to do it on that basis (line 62).

Desire for the intervention is seen in the council and the psychotherapists. Beth spoke about being "offered" psychotherapy nine times in the interview, with no mention of any wish for it herself (see quote 34).

The theme cluster, *diminishing,* came through material about Beth's life situation, the impact of the autism and her relationship with the intervention.

Quote 31

> I can't remember if I was at the back-end of maternity leave from Samuel and then, because the City is really great about people having babies, you then get fired so (laugh). I was then job-hunting, so even though (pause) it was not great for me from that point of view it was actually good because I was around a lot more than I would have been had I been working so I was able to come to the sessions and stuff (line 69).

In this moment, I felt that Beth diminished the impact of this extremely difficult experience (delivery - laugh), and focussed instead on how "it was actually good". A similar idea of *diminishing* the significance of a situation was evident through Beth's use of language. She repeatedly used the phrase, "it doesn't matter" (see quote 37). When I asked about the ending of the work, I had a sense of *diminishing* any significance of the ending by focusing on the next thing and on how little meaning, in her view, the ending would have had for James.

Quote 32

> I can't, I can't actually remember the last session. I wasn't suddenly feeling either oh, you know, oh my word how am I going to manage without the sessions, all this. I think it was just one of those things that's, that's done and it's, move onto the next type thing. Because there's all, with the school he's at, there's always a something. You know, and is now actually he doesn't get OT anymore but we've got problems of trying to get him to type, actually I must remember that for next week, erm, so there's always a something, so it's not something like, oh yeah, that's finished, off you go, bye bye. Do you know what I mean? There's always some kind of support or help or whatever, so I, I don't remember a clear, you know, ending. As for James, it's not like there's going to be some great big goodbye that he would have had with Kira. He

> was, you know, he was four, he would have been just coming up for five then. It’s not going to mean a lot, is it. So, so, I don’t have a view really either way on that. I mean I think everything was well managed (line 660).

Here Beth does not differentiate between psychotherapy and any other intervention. She remained in a neutral position, not having a view either way (*avoiding knowledge/desire*). Speaking about her son’s relationship with the intervention, Beth said, “so I think he was probably like, neutral, it was probably just a thing to do” (line 512).

Relationship with personal capacities

The *diminishing* theme can be seen in this next quote in relation to the intervention along with feelings of *guilt.* Beth was speaking about her view of the intervention as focused one-to-one time.

> Quote 33
>
> he just needs people to engage with him, which is what it is at the end of the day isn’t it, and sure one-on-one time is great if you could always do that, to really spend a lot of focus time on them. So, but, yeah, I don’t (trails off) (line 476).

I thought about what is not possible for parents, both in terms of external circumstances and also internal capacities or resources, and the feelings that might be present when a professional is able to offer your child something that you are not able to.

The material around *fear of causing damage* mostly related to the intervention/service. At the beginning and again at the end of the interview, Beth asked me whether the purpose of the research was to make decisions about whether child psychotherapy would continue to be available as an intervention. I felt there was an underlying concern that her comments might cause significant damage.

The following quote contains an idea of an intervention being damaging.

> Quote 34
>
> autism, the whole thing was completely new to me, I just think I was, like I said, I was wanting to take, as long as people weren’t trying to give him electric shocks or something (laugh), you know I just took a view that, if this is being offered, surely it can only help (line 167).

There were few occurrences of *Fear of causing damage*, however it appeared significant. This will be considered further in the discussion chapter.

Personal capacities

There is material in the interview where I felt that Beth was making a comment on an awareness of her state of mind and *personal capacity* at the time they were involved in the psychotherapy.

> Quote 35
>
> I do think if I had it now it would probably be a very different experience (pause).Tricky one isn't it? Yeah, and it is a very, very, it's a very personal thing, yeah but, generally I'm very grateful for all the help and support he's had (line 783).

The content, choice of language and my associations were all sources of evidence here. I found Beth's use of "I" significant. Although she was reflecting on how it would be for James to have psychotherapy now, she appeared also to be considering how it might be a different experience for her, perhaps with different possibilities.

Family 2 – Relationship with help and change

The sub-ordinate themes which sit under this super-ordinate theme are those which capture the participants' relationship with help, their experience of the interaction and any changes they perceived in the family and/or child.

Exposed and excluded

For this participant, theme clusters of *excluded/rejected*, *critical judgement*, and *demanding/disappointing other* gathered under this sub-ordinate theme.

Beth's data included material related to feelings of *exclusion* and *rejection*. In the following extract, she describes an experience of not being offered a particular intervention by the service.

> Quote 36
>
> One thing I didn't ever go on, I didn't get invited onto was the, um, they used to get the parents, they probably still do it, the parent talks, to kind of start telling them what it's about. Oh it's on the tip of my tongue what they call it. So there are some parent groups. I think if you had your child newly diagnosed

> and you're just kind of, you are sometimes given these information packs. It's like, good God what on earth am I meant to do now? (R – hmmm) And they had some parents groups. You go along to talk and they tell you this that and the other. I can't remember what it's (pause) Early Bird, is it Early Bird?
>
> R mmm
>
> B Yes. And I think one time I was told that I wasn't invited onto it because it was quite popular, 'cause they said, you kind of seem quite up on what's going on and know what you're doing so I never got invited so I'm like, okay, fine (line 238).

Beth repeated that she was not invited three times. My association was to her experience of not being invited into James's therapy sessions (*excluded*). This theme was evident in the content at other moments in the interview when she made reference to not being included. "I wasn't actually in the room" (line 170), "I know they were his lessons" (line 204), "they were kind of private between her and, and James and, like I said, he wasn't of an age to talk about it with" (Line 210). "He was so young then and I didn't get any feedback from him, like I said, it's hard to know how it, how much it affected, impacted him" (line 730).

In the quote above (36), Beth touches on her vulnerability at this moment in the family's life, "God, what on earth am I meant to do now?" Her final sentence was delivered in a strong tone of voice with some annoyance which brought to mind adolescent feelings of something unfair. It did not seem "fine". I felt that here was an idea of *disappointing other* who did not recognise her need. Following this passage, Beth spoke about her lack of need for the support (quote 29) of other parents, claiming, "I had enough on my plate as it was". There seemed to be a picture of a *demanding other* who would drain rather than add value to her life.

Data which clustered around the theme of *critical judgement* included a sense of having to get things right; a world of right and wrong. In the following passage, which begins with content about Beth's criticism of those who are "flaky" in their commitment to therapy, Beth communicates something about her experience of the assessment period.

> Quote 37
>
> the last thing you want, I imagine, is someone two or three months in saying, ah, I'm not sure, I can't do it or, not showing up for sessions, or showing up late which is just quite frankly very rude, erm, that (pause) so I'm sure it must

> be hard, and I did, and this is just my own personal thing, no one ever gave me an answer for it, is that I, I got the impression that I, I was being checked out as much as James to make sure that I could meet the commitment.
>
> R Right, before, you mean in the assessment period?
>
> B Yeah, and you know, no one ever gave me an answer to that and it doesn't matter but that's my, I strongly believe that and I can understand why because if you think someone is going to be a bit flaky about it, there is just no point in you doing it if suddenly a few months down the line they, they, they stop. And also, though I wonder, once again it kind of doesn't matter, I don't need an answer for it, is, I would imagine, though I don't really know that maybe you look at, well this is what I just felt that the time, that you're kind of going to look at a child and think is it worthwhile for the child? Are they, could they get something out of it? And I don't know if that's how? Where they are on the spectrum or is this the right age or time for them, there must be a lot of factors to think because I imagine you've got a lot more children you could be offering it to than you've got the therapists or the time. And so sometimes you think I wonder why they've picked me and this that and the other but I guess it's probably a lot of those factors put together that you make that decision I suppose, I don't know. I ask a lot of questions generally (laugh) (line 342).

In this passage, I noticed that Beth did not actually ask the question and stressed that she did not need an answer (*avoiding knowledge and desire*) also repeatedly stating that it didn't matter (*diminishing*). I felt that, in amongst this wordy account (*distancing*), using evidence from delivery and association, the crucial phrases were "I was being checked out" and "I wonder why they've picked me". Here there seemed to be an idea of a critical other with some concern about what had been noticed.

As Beth repeated phrases about never having been given answers, I thought about the *disappointing other*. This was supported by my feeling that I was disappointing in not being able to provide answers. These feelings surfaced a number of times during the interview.

Desire for help

During the analysis, a theme developed around feelings of *anger with connecting.* In quote 28, Beth mentions her irritation at repeatedly forgetting the name of the parent worker. I thought about her irritation at an idea of being asked to reflect on loss and difficulty (see quote 23) which can perhaps be seen in the following material.

> Quote 38
>
> He hasn’t had to have that school conversation where they tell you, you have autism. It’s a bit like telling your child they’ve got blue eyes. It’s like, it’s flippin’ obvious, they know, you know (line 755).

I wondered if, for this mother at this point in her life, making contact with feelings about a vulnerable reality did not feel helpful. Beth described an idea of the wrong kind of help in the following quote.

> Quote 39
>
> yeah and then I asked to then push them out and then I kind of said I (pause) Yeah, I just didn’t, yeah, for me, so I didn’t really feel, yeah, I didn’t really feel I needed it. If someone was saying, yeah, we’ll come round to your house for one hour every Saturday and help you out or take the kids out, that would be, in you come. You know, I, I felt I needed concrete help, I didn’t need to sit and talk to someone about it, you know, but it’s different for everyone, at different stages (line 644).

The theme clusters *rejected/excluded*, seen in the “in you come” or “push them out”, and with the reflection on *personal capacities* as well as perhaps *fear of causing damage* to the service in “it’s different for everyone, at different stages”, the content of this passage confirms an idea of not wanting this kind of help for herself at this time.

Therapeutic gains

This sub-ordinate theme brings together positive feelings about help and support, about the intervention, changes for James and an idea of crucial help for her child.

Beth was consistently measured in her comments about the intervention. She spoke about her general feeling that things were improving for James at the time he was engaged in psychotherapy, although stressed that she could not say either way whether the psychotherapy played a part in that. She spoke about the helpful nature of a containing structure which is integral to the school day as well as to intensive psychotherapy.

> Quote 40
>
> you know they are changing and growing all the time so I couldn’t I, I couldn’t say either way. But I guess when he was in reception I was very happy with generally how things were because he had lots of friends, I think the schooling and the structure and all that kind of thing helps, you know, he was reading

> well, you know, he seemed basically, he was managing in class so, so you know I think things seemed, seemed okay and he was improving in his ability and whatnot all the time (line 696).

In the following quote, there is a rather different feeling, one of the intervention as crucial help for the child that had to be managed and in spite of severe logistical difficulties of attending three times each week.

> Quote 41
>
> families have different experiences of different things to deal with that, and you know, what might be okay for one family is really tough for another and I don't think you can really compare them. Yeah, so ...
>
> R So when you started, can you remember back to how it felt to be doing that three times a week?
>
> B erm, I can't (pause) just quite full on, time consuming (mumble, laugh) just logistically hard, just trying to manage it. I don't, it was just another thing, but I felt I had to do it, I kind of knew I had to do it, it wasn't a, oh do I think I can manage to fit this in, it's like, it's happening, I'm going to have to figure it out. Erm, so it was more that, yes, it's just, it had to be all about James and everything, whatever I could make work for him really (line 300).

This quote starts with what could be considered a reflection on *personal capacities*. I thought about the parent sessions being really tough for this mother at this time, with feelings of a *demanding other* evident in the "full on, time consuming ... just another thing". Her description of her commitment made me think about the need to make sure he was getting every possible intervention, as she put it another moment, "let's face it, he's done everything going" (line 541). But also, there seemed to be some sense of something valuable that she just had to make happen for her child.

Beth expressed her gratitude for "the whole package" (quote 35) and "all the help and support he's had" (line 793) whilst wondering about the possibility of James having more psychotherapy now or in the future. These wonderings occurred (total of) 9 times during the interview. This material clustered under *hopeful wonderings.*

> Quote 42
>
> I don't know if it would be beneficial for him, for him to have it again, I don't know if people have it for going to secondary school, I don't know if year six is a good time, because there's a lot of change then, so while I can't say oh yes I could see that age three and four he really changed in this way, I still think I would consider it again if it was being offered (line 116).

I will now present the themes for family 3 in figure 24.

Figure 24: Table of themes – family 3

Family 3								
Super-ordinate theme	***Experience and impact of loss***			***Relationship with feelings and the self***		***Relationship with help and change***		
Sub-ordinate theme	***Loss of the typical child in context***	***Impact of loss***	***Unwelcome responses to loss***	***Relationship with feelings***	***Relationship with personal capacities***	***Exposed and excluded***	***Desire for help***	***Therapeutic gains***
Theme clusters for this family	***Deathly***	***Life-changing shock*** ***Unsteady foundations***	***Punishing critical voice*** ***Humiliating exposure***	***Avoiding loss*** ***Pull towards loss***	***Guilt***	***Not present***	***Desire for help***	***Understanding beyond words*** ***Establishing foundations*** ***Life-giving help*** ***Hopeful gratitude***

5.3.3 Family 3

The family consists of the mother participant, Amran, her daughter, Jemima and the father whose name was not mentioned. English is a second language for Amran, and Jemima is non-verbal. Jemima received intensive psychotherapy for two years and work finished one year five months before the research interview. The therapist's name was Sian. We met in the clinic where the intervention took place.

Family 3 – Experience and Impact of loss

The experience and impact of loss is a particularly significant theme for this participant, occurring 124 times in the transcript.

Loss of the typical child in context

Amran communicated her feelings about Jemima's diagnosis extremely powerfully. Data from the interview suggested an experience of something extreme, severe, enduring, repeating, stuck, depressed, with a sense of being unable to see. A *deathly* theme cluster emerged. In the following extract, Amran described her feelings at the beginning of the psychotherapy.

> Quote 43
>
> nothing is going to work with Jemima at all. She would, she would stay like that for the rest of her life. She will not go anywhere. She will not improve. She will not progress at any means. Um, I was convinced, maybe because at that time, all the things was association, associated with my feelings and the devastation of giving the diagnosis of autism and she will stay like that, nothing will happen. She, she, she will miss out lots of things in life. She, she would stay like this. I was so depressed. I was so (pause) I was in distress you can say. I didn't even pay attention at the beginning of these sessions at all. For the first two or three weeks I just brought her here blindly (laugh) (line 228).

Amran communicated a lack of hope, devastation, distress and feelings of depression. The content, language and delivery in this extract all provided evidence to support the validity of the *deathly* theme. Amran spoke the final sentence with a tone of incredulity, as if there was something incomprehensible about the way she felt at that time. Themes of repetition and feeling stuck came through Amran's language and content as she became stuck in trying to describe the devastation of this experience, her "very severe depression" (line 363), repeating herself with a sense of no way out. At such moments, I felt that we lost sight of her daughter. At times, I became concerned about Amran's state of mind and felt I needed to help her out of this stuck place. I will consider my role in this moment in the final chapter.

Impact of loss

For this participant, this sub-ordinate theme of *impact of loss* includes data clustered around *life-changing shock* and *unsteady foundations*.

Alongside the content, my emotional response during the following material provided additional validation.

> Quote 44
>
> because, err, I believe my child, erm, my life was completely changed when I received the diagnosis, the day. I still remember the day that Jemima had diagnosis of autism which is in 2013, 27th of March and it was on this room.
>
> R - In this room?
>
> A - In this room in particular and I was sitting in here.
>
> R – hmm
>
> A - The doctor was here and other professional, professionals were sitting around. Yeah and when I had the news that Jemima had autism, although I knew beforehand, I was in suspicion, still I was in suspicion that it might not be autism when I received the news I had like nervous breakdown in this room and the doctor to just arranged for another meeting because it was very, it was very hard day for me. I was crying loudly and I couldn't control myself. Even Jemima's dad was in tears. We were both in tears and she was here playing on the table innocently without knowing what's going on. (Pause) yes, I think from that day 2013 my life completely changed (line 324).

As Amran told me about the devastating blow she experienced in the very room we were now talking in, I felt a ripple of shock and disbelief, evident in my clarification "In this room?" Use of language also provided evidence. Whilst being particularly aware that this is not Amran's first language, her slip "my child, erm, my life completely changed" seemed significant as she went on to describe how, even though she had suspicions about her daughter's difficulties, the moment she received the diagnosis changed her picture of her daughter in her mind, a devastating loss.

A theme of *unsteady foundations* emerged which brought together material suggesting nothing solid, something fragile, indescribable and unbelievable, without meaning and beyond words (see quote 43). The content of the next passage describes an idea of nothing solid in place.

> Quote 45
>
> Err, first of all, Jemima has the condition of autism and she was diagnosed of that at three years of age. And once she was diagnosed with language problem (R – mmm) and severe learning difficulties (R – mmm) so Jemima was all over the place. (R – mmm) There was a problem with everything (R – mmm). Small tasks with Jemima, like washing hands, brushing her teeth, giving her a shower (R – mmm), feeding her, lifting her up, doing her hair. Everything was a struggle with Jemima (R – mmm). I have, I have to admit to, at some points I wasn't patient at all. I was so depressed. I was seeking advices, advices from so many people (R –mmm) (line 117).

I noticed how many times I interjected in this extract and identified a desire to communicate some understanding, in response to a feeling that what she was trying to describe was beyond words.

Unwelcome responses to loss

The above (quote 45) contains an example of a *punishing critical voice* which developed as a sub-theme in Amran's data. This related to material about feelings of hatred, criticism, anger and frustration towards the autism and her child. Amran states "I have to admit to, at some point I wasn't patient at all", touching on her frustration and anger. With the phrase "I have to admit" I thought about feelings of self-criticism and *guilt* in response to these unwelcome feelings towards her child. In quote 44, when receiving the diagnosis, Amran said, "and she was here playing on the table innocently without knowing what's going on". She seemed to be talking about her daughter's apparent unawareness of her parents' distress. However, I also felt this contained a sense of Jemima inflicting the devastation (see quote 49).

Amran's account contained material relating to the loss of the typical child experienced as a *humiliating exposure.* In the following extract, Amran describes how difficult she finds her daughter's behaviour in the street alongside information on how much better things have become since progress has been made with Jemima's understanding.

> Quote 46
>
> Um, at the street, she was very, very difficult with me in the street. She just drop herself didn't want to move, didn't want to walk. And she had obsessions with buses and she had a sense of um, of um, not aware at all of the danger around if she runs off to the street towards buses. But nowadays, when we walk in the street, she reduced dropping on the floor (R – mmm) and she very patient when we want to cross the road. I tell her, Jemima this way, green man will come soon, that's red man. Green man is coming soon. When the green man appears I say, Jemima green man, let's cross, cross, cross. She understands. And then she stops, or you can say that her obsession with buses started to be reduced like bye bye buses. But she, she still ask me to raise my hand and wave to the bus (laugh). And in a way I find it embarrassing in the street just to wave my hand and, raise my hand and wave to buses. It's not, it's just the attitude or my, maybe people look at me as somebody (pause) maybe, yeah. Anyway I didn't really care a lot but (line 169).

As Amran spoke of her embarrassment, her pained tone of voice, the uncomfortable laugh, and her thoughts about what other people might think (*critical voice*) suggested stronger feelings of humiliation and exposure.

Family 3 – relationships with feelings and the self

Relationships with feelings

For Amran, the data suggested themes about the central nature of loss, apparent through material relating to *avoiding loss* and a *pull towards loss*.

In the following quote, I had asked Amran for her reflections of the ending of the work. Her mind turned to her wish that it had not ended.

> Quote 47
>
> Jemima had lots and that's true, Jemima had lots. But I'm still, I'm still eager and think that it's important if Jemima has more and more sessions. I hope these sessions not finished with Jemima. I hope these sessions can, can just introduced to Jemima again (line 404).

Here I felt was a sense of something that should never end, with the words "more and more". Amran spoke about endings and losses very readily. In the following extract from early on in the transcript, she describes her daughter's engagement with psychotherapy.

> Quote 48
>
> As soon as we come into the building, she knows which door Sian will come from, so she immediately rushed to the door and waited and she was eager to go with her, to the room and play, explore things. They spent one hour or like 50 minutes and Jemima came feeling happy, relaxed. And I could sense that maybe she wanted to stay more with her. Sadly she left after one, one year. I was in tears when she left and I guess Jemima, of course Jemima is non-verbal. She, she hasn’t spoken yet. But I could sense that Jemima just felt that she is not there anymore (line 52).

The words “not there anymore” to my mind contained an idea of nothingness, something *deathly*. Throughout the narrative, I noticed how moments of loss became the focus of Amran’s narrative even when my questions or prompts had not been concerned with endings or losses. For example, when I asked Amran about the parent sessions and she told me about her sad feelings when the parent worker left. The theme of a *pull towards loss* emerged through repeated examples of this (nine examples in total).

Relationship with personal capacities

In quote 45, it’s possible to see feelings of *guilt* when Amran spoke about having to admit to her lack of patience. In the following example, Amran spoke about the struggle.

> Quote 49
>
> So, we were both struggling, yeah. I just kept buying like lots of toys, lots of things, trying to, to work with Jemima on so many areas like how to be erm, how to be cooperative, in a way, when I do small things with her, like for example washing hands, brushing, sitting on the table and give her food. So these are small things. I was struggling. And she, she gave me really hard time for that but of course I understand her condition (line 132).

Here Amran communicated something of the overwhelm and desperation she was feeling and referred to Jemima giving her a “really hard time”. I identified a sense of punishment coming from Jemima and criticism towards her (*punishing critical voice*), and then feelings of *guilt* in Amran’s desire to be understanding.

Family 3 – relationship with help and change

Exposed and excluded

Although there are examples of feelings of exposure in response to the symptoms of autism, this theme is not present in relation to the intervention. This will be considered further in the discussion section.

Desire for help

This sub-ordinate theme is concerned with the desire for connection and eagerness for life. It can be seen in the earlier material (quotes 47 and 48) where Amran talks about her daughter's engagement with the psychotherapy, and also in her description of "seeking advices" (quote 45).

> Quote 50
>
> After a while I could see Jemima started to improve. Her toys, games at home were in a corner, believe me, just touch them and look at them and although I, I made lots of efforts of playing with her but she didn't seem interested at all. But when the psychotherapist sessions started with her, I could see that she was eager to do the things with me at home. So you can say it was like integrated work um at home and at (the clinic) here with the psychotherapy. So I was, I was so happy, I was so happy with that (line 89).

The use of language was particularly important in validating this theme. As in this quote, the word "eager" was used repeatedly in the transcript.

Therapeutic gains

There was a significant amount of data relating to therapeutic gains for this participant which became clustered around the following headings: *understanding beyond words*, *establishing foundations, life-giving help and hopeful gratitude.*

The theme cluster u*nderstanding beyond words* included material about being able to see, developing understanding, communication, working together and linking up. In the above quote (50), Amran spoke about feeling the psychotherapy work was "integrated", joined up. She appeared to feel included in the work with her daughter. Describing her daughter's desire to explore toys with her, she claims "I could see" in contrast to the "brought her here blindly" at the beginning of the intervention (quote 43). This imagery is present in other moments, such as when Amran described her experience of feedback she received from the psychotherapist after each session about what they had done with Jemima that day. Amran reflected “so the picture was very clear for me”, (line 280) and “so I wasn’t in darkness, on the contrary” (line 282).

An additional source of evidence for this theme was my experience of feeling I became a link for Amran when she seemed lost and stuck in describing her depression and collapse. At one such moment, I mentioned the parent session taking place immediately following our meeting which Amran had forgotten about. She replied with “yeah, you remind me,” with some relief and gratitude in her voice. I felt she was able to use me as a link to something helpful.

Understanding beyond words is present in the following extract when Amran describes the development of Jemima’s understanding, explaining “I could feel it, I could sense it”.

> Quote 51
>
> And then things started just to be collected again and put on a basis, you see what I mean? Jemima began to be more patient. Although the progression was very slow but I could feel it, I could sense it. Jemima began to understand some words like, Jemima come here, let’s go to the bathroom, time for washing, wash hands, Jemima, come here, let’s, let’s have dinner. So there was, there was more understanding. And Jemima started to settle, yeah. Before, before the psychotherapy sessions, Jemima was not settled at all. And there was lots of noise and vocalisations, sounds, (R – mm) frustration, and it all expressed in crying, because I know she cannot express herself, so when she wants something, and I got stuck. The way of expressing herself was crying, screaming, like making lots of tantrum, so it was very difficult at the beginning (R – mm) I struggled a lot to be honest. But with the psychotherapy session, I could see the progression. More understanding, more settlement, more patient, um more, more, more knowing of how to play in a meaningful way. So, and I know this will broaden her mind, this will contribute a lot in her development as a child (line 135).

Material related to developing understanding (also see quote 46) was in contrast to an idea of something incomprehensible and without meaning (see Quote 43, *unsteady foundations*).This quote (52) shows an example of the theme cluster *establishing foundations* through the slow, steady progress and an idea of a broadening mind. Amran spoke about this when reflecting on the gains she felt through the parent sessions.

Quote 52

> But the crying that I had after the diagnosis was unbearable (R – hmm, in-breath). But it helped me a lot in releasing lots of things inside me. After each session at the beginning, it was very slow, but I felt relieved after each session. I I I was feeling that I was a bit light when I came in at the beginning so they were very very useful, I can't deny that, I cannot, yeah (line 380).

Amran begins with the unbearable nature of her collapse. I felt concerned that she would become stuck in this again and felt compelled to help (my in-breath). She then gets hold of something helpful and begins to talk about her return to health. Here was relief and a sense of a slow, steady recovery through the repeat of "after each session", which links to the experience of the feedback from the therapist which she also described as occurring "after each session" (line 272). A theme cluster developed around the idea of *life-giving help* (in contrast to the *deathly* theme) which included material on a slow, steady, drip feed, the crucial nature of the relationships and help received as well as a sense of fundamental change brought about in Amran's mind by the intervention, which the following quote illustrates.

Quote 53

> Jemima became a different person from when she was three-year-old. I know there is the natural development as a child but she is, she is growing differently I know (line 420).

The theme cluster *hopeful gratitude* can be seen in quote 48 when Amran spoke about her daughter's growing relationship with the therapist. She referred to the significance of this as well as her pleasure later in the interview, saying, "I was so pleased with that because I could, I could understand that Jemima has feeling towards people, not just me or her dad" (line 253). Quotes 50 and 52 also provide evidence through content and language of joy and relief in progress both in herself and in her daughter. This final quote provides a further example of *gratitude*.

Quote 54

> But with the psychotherapy session, I could see something in these empty cups and it was very impressive for me and it was very touchable because that was the first time I could, that the psychotherapist, er, introduced different toys, um, games. For example I do remember that there was a a favourite doll for Jemima and there were like cup of tea sets and that was the first time that Jemima knew that someone can drink something like tea. So they started, um, with the doll giving her tea. And then at home, Jemima brought me some cups and she was trying to give me something in these empty cups and it was very

> impressive for me and it was very touchable because that was the first time I could see Jemima doing something useful and made the association between a cup, a glass and the process of drinking. Do you see what I mean? (R – yes) It was wonderful for me and (sigh), yeah (line 72).

As she spoke, I thought about the image of the empty cups and the painful idea of a daughter who was not “useful”. Amran’s tone of voice as she spoke about how “wonderful” it was for her to have an experience of her daughter as someone who could develop and whom she could take pleasure in was a source of evidence as she appeared to feel the joy she felt again as she recounted it. Amran used the word “wonderful” a number of times in the transcript (lines 43, 45 and 308) to describe the clinicians. This theme of gratitude was supported by my strong feelings of gratitude towards Amran at the end of the interview.

Summary

This section concludes with a summary table which illustrates links between themes and across all three families. The links are highlighted in the same colour. A key to the highlight colours is shown in figure 25. I will give further consideration to the relationships between themes and across participants in the discussion chapter which follows.

Figure 25 Key to colours in figure 26

Bold	Dominant theme for the participant
Red	Loss and lack of hope moving to relief, gratitude and hope
Purple	Shock, ungrounded feelings moving to establishing foundations
Yellow	Relationships with knowledge and understanding
Green	Self-protections and engaging with pain
Blue	Disbelief across themes in family 1

Figure 26: Table of themes across participants

	Experience and impact of loss	*Relationship with feelings and the self*	*Relationship with help and change*
F1	Loss (child "behind opaque glass")	Engagement with pain	**Exposure** **Feeling excluded** **Disbelief/scepticism/ambivalence (towards intervention)**
	Shock and disbelief in level of impairment Ungrounded	Murky confusion	**Overcoming (able to benefit from the work)**
	Hatred/anger	Guilt	**Linked up understanding** **Crucial important of help/experience (for parent and child)** **Relief/gratitude/joy**
F2	Pragmatic attitude to loss and difficulty	**self-protections in place**	Excluded/rejected Critical judgement Demanding disappointing other
	Crazy overwhelm Vulnerability Self-protections needed?	**Neutral position** **Distancing** **Diminishing** **Self-reliance** **Avoiding knowledge and desire**	Anger with connecting (wrong kind of help – withdrawal from parent work)
	No occurrences of unwelcome responses to loss	**Guilt** **Fear of causing damage** **Personal capacities**	Hopeful wonderings (gratitude for "whole package")
F3	**Central nature of loss** **Deathly (no hope - diagnosis experienced as trauma. "Severe depression" in mother - self protections failed)**	Avoiding loss Pull towards loss No occurrences of distance from pain	No occurrences of exposure/exclusion
	Life-changing shock **Unsteady foundations** **(Lack of meaning)**	Guilt	Desire for help
	Punishing critical voice **Humiliating exposure**		Understanding beyond words - Establishing foundations Life-giving help (for parent and child) Hopeful gratitude

Chapter 6 Discussion

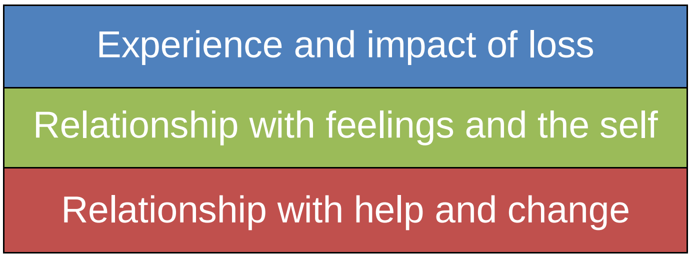
Introduction

The aim of this chapter is to discuss the findings outlined in chapter 5, placing them in context. Rather than the idiographic presentation used in chapter 5, here I will organise the discussion thematically, drawing together the relevance across participants and describing links between themes. I will use quotes from the data for emphasis and to re-familiarise the reader with the themes. Where quotes have not been referred to previously, I will give line numbers from the transcript as an indication of the position of the quote in the interview.

I will provide context for the study findings through a consideration of material from the reflective journal. I will describe how the findings relate to the literature discussed in chapter 1 and draw on additional texts when helpful. I will re-visit the meeting (pre data collection) with an experienced clinician in the field and consider how the themes relate to the issues discussed. Placing the themes in context in this way addresses theme validity by providing triangulation for the findings.

Figure 27 provides a reminder of the three super-ordinate themes which emerged from the data analysis.

Figure 27: Super-ordinate themes



6.1 Experience and impact of loss

“just get on and deal with the child you’ve got”

Figure 28: First super-ordinate theme with sub-ordinate themes

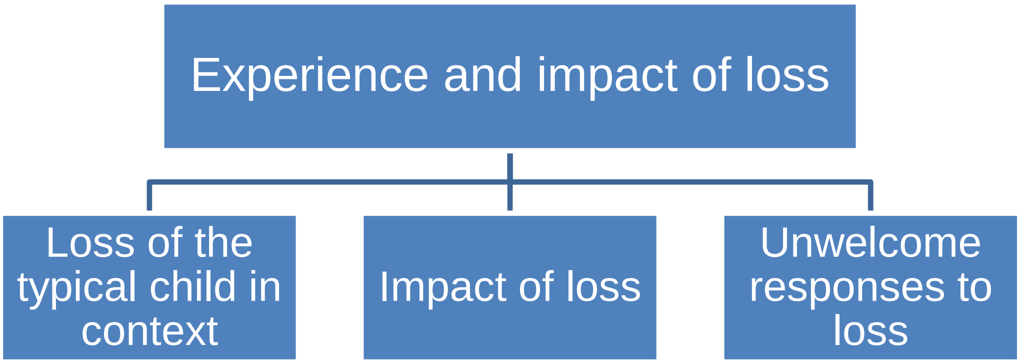


Figure 28 illustrates the first super-ordinate theme with the three sub-ordinate themes which cluster beneath it. I will begin by drawing together the relevance of this theme across all three participants before discussing each of the sub-ordinate themes in turn.

Relevance of theme across participants

Despite significant differences in the presentation of the theme of loss, all of the participants experienced it. It is notable that loss material in the data is particularly present in relation to the symptoms of autism in the child before the intervention began. For family 1, the child is felt to be behind opaque glass, with a sense of disbelief in the severity of his symptoms. For family 2, there is a pragmatic relationship with loss with some distance from the impact of it. The loss theme has particular significance for family 3 (a dominant theme) where loss is experienced as something deathly, enduring and devastating, resulting in depression in the mother. The theme has particular significance as it sheds light on other themes in the participant’s data.

6.1.1 Loss of the typical child in context

Child as extension of self

Data related to the *loss of the typical child* was present in all three participants in the study. The emergence of this theme supports Bicknell's (1983) findings which focused on mothers of children with a learning disability and described their experience of the loss of the hoped-for "perfect" child.

Solnit and Stark (1961) and De Groef (1999) wrote about how the parents of a learning disabled child experienced the loss of the perfect child as a reflection on themselves, causing damage to the ego. I recognised elements of this in the study data. Christine's comment, "we'd wake up in the morning and he'd (force) chewed his bed" (quote 4) seemed to contain disbelief: how could *our* child have this level of impairment? Amran reflected, with a pained and sensitive tone, "maybe people look at me as somebody" (quote 46). She appeared to feel that if people saw her daughter behaving oddly, they might also identify the oddness in her. (Here is a link to the *humiliating exposure* theme).

These findings brought to mind my work with a child with Proteus syndrome who had an extremely misshapen and oversized head. The mother, a highly educated, respected member of her community, described her frequent experiences of people in the street, looking first at her child and then instinctively at her face, as if expecting to see a mirror image. In her pain and fury, the mother at times responded by puffing out her cheek to make her face in some way resemble her child's. In this study, all of the participants were articulate people from high achieving/academic families (interestingly, Amran did not draw my attention to this context herself but I learnt about her academic background after the interview from a different source). In the peer discussion, the therapist reflected on the particular nature of the loss of the typical child and the blow to the self in this context.

Emanuel's (1997) idea of a "primary disappointment", when a mother has a baby with a disability, seems relevant to the experience of mothering a child who develops autistic symptoms, "when her innate expectation of what she will be a container and mother to, is not realised" (p281). Emanuel considered the consequence of such a loss. Mothers could struggle to sustain an ongoing effort to know and understand their child (Bion's concept of 'K', 1962), resulting in a problem seeing the child clearly for who he is. There are perhaps links to the *relationship with personal capacities* theme (feelings of guilt) discussed later in the chapter.

Recapitulated grief

The participants' data supported an idea of a repeat or return to the experiences of loss as the child grows and the family develops. Goldberg *et al.* (1995) wrote about an idea of recapitulated grief within the field of learning disability. "At each major life-cycle stage (particularly the death of a parent) memories of previous loss and grief are invoked for each of the family members" (p267). This idea seemed present in Christine's data when she spoke about the strong feelings in her son on the birth of new siblings. I thought about how this major life-cycle event may involve a recapitulated experience of the loss of a typical child. Beth's data also suggested a returning sense of loss when she spoke about her son's relationships at school. "In reception they would have had no idea that Austin had autism or was different. Now at school they do" (family 2, line 745). In the peer discussion, the therapist stressed how extremely hard the progression from early childhood to latency can be for parents. Difficulties start to become more and more apparent as their typically developing peers continue to gain skills. Birthdays can be particularly poignant in this context. Tobin *et al.* (2012) found that parents had to "adjust their expectations and beliefs about their children's future" (p82) when their children with ASD transitioned to secondary school.

Recapitulated grief links to the pain of loss being re-felt as it is recalled and discussed. This was evident when I asked Beth how she had felt at the time the therapy started. As she recalled the overwhelm at that time in her life, her feelings seemed to become current. For Amran, there was a particularly powerful experience of recapitulated loss as she recounted the story of Jemima's diagnosis which had taken place in the same room as our interview. Re-feeling loss as it is discussed links to the third super-ordinate theme, *Relationship with help and change*. As Klauber described in 1999, engaging with help can involve "the dreadful stirrings of the memory of noticing something was wrong" (p36).

Loss of hope

The experience of loss as something *deathly* is particularly present in the data of family 3, where, at the pre-therapy stage, there is felt to be no hope for any change or development. Amran felt Jemima would “stay like that for the rest of her life. She will not go anywhere” (quote 43). Amran vividly and repeatedly described her depression, her loss of interest in the world, herself and her child. Strikingly, the diagnosis itself was experienced as life changing, a kind of death sentence, not only the symptoms in the child. Beth’s data also includes a lack of hope when she spoke about non-verbal, autistic children who will not speak: “It’s just how it is” (line 629). When she described her reasons for not wanting to attend the parent sessions, Beth said that she was not looking for answers and there seemed to be little point talking or thinking about her son’s autism, “he’s got it, we’re dealing with it” (quote 28). Durban (2014) understood this difficulty with hope, suggesting it might sometimes feel safer for parents of children with autism to become stuck in despair rather than risking the possibility of hope for change.

These data showing a lack of hope link to the idea of autism as an organic deficit, a static condition without any possibility of development (Symington, 1981). Here a way of managing internally - not allowing any glimmer of hope - could also be reflected in the larger cultural response to the autistic condition.

In the peer discussion, the therapist spoke about hope for parents as a dangerous thing. She described how progress for such children is often not linear, explaining that small steps can become huge in parents’ minds and it can then be extremely hard to reign in their hopes. With each disappointment comes a recapitulation of grief. A complex relationship with hope can be seen in family 3 when Amran says that her daughter “hasn’t spoken yet” (quote 48). Here is the very difficult line between holding on to hopeful signs of progress and accepting the limitations of the child and the intervention (Reyes-Simpson, 2004). Klauber (1999) considered this balance to be an aim of the parent work, “to monitor honestly the signs of real hope and improvement, along with evidence to the contrary” (p41).

Loss of hope links to the sub-ordinate theme *therapeutic gains* discussed later in the chapter, where hope re-emerges in the data.

Loss in context

Two of the families mentioned significant losses in their history. Beth touched on the loss of her parents - “you know, parents died years ago” (quote 23) - and a decision to have children without a partner, “I had them on my own” (quote 27).

(It was striking that one of the assumptions I realised I had had when interviewing Beth in her large, beautiful apartment was that she had a wealthy partner, also earning a significant salary, until she told me otherwise. I wondered later if the thought of her so alone with this loss was initially too painful to make contact with, and so I too stayed away from it – *distancing*.)

When describing her depression, Amran explained, “I just wanted to keep, keep myself to myself ... I didn’t even have, I just wanted to talk to my family back home. They are still back home, they are not here. In (*home country)*. I just wanted to talk to my Mum and my brothers” (line 344). Here there is a cumulative loss of family support and home country. The mention of her home country also brought to mind potential experiences of war of which I can know little.

In Smith *et al.*’s (2009) description of the hermeneutic cycle, they considered “the dynamic relationship between the part and the whole” (p28). I thought about how an experience of loss sits within the context of other losses in a person’s life and the ways it has been possible to manage them internally. Klein (1940) described how we all lay the foundations for managing loss in our earliest experiences, as infants when we work through the process of weaning. For these parents too, the loss of the typical child does not occur in isolation and its impact may be compounded by previous life experiences and the ways they have been experienced and processed.

Loss of the intervention

Also striking in the data were participants’ communications about the loss of the intervention. I recognised a moment of something deathly when Christine described the loss of vibrant life that came about as a consequence of the house move to the country where “there was nothing”. She explicitly communicated the enormity of the loss of the intervention using powerful religious language. I wondered whether the loss of the psychotherapy (alongside the support and understanding experienced at school) took her back to a desperate, hopeless time before such help had been available. When I reviewed my thoughts recorded immediately after the interview in the reflective journal, Christine’s painful descriptions of how hard she found the ending of the parent work had particularly stayed with me.

For the other two participants, the loss of therapy is kept at a distance in different ways. Amran communicated wanting therapy never to end for her daughter, “it’s important if Jemima has more and more sessions” (quote 47), whereas Beth described an ending which had little meaning, focussing instead on the next intervention or activity. Here, the sub-ordinate theme, *relationship with painful feelings,* sheds light on the participants’ relationship with the ending of therapy. In Amran’s data, I saw a desire to avoid the loss, and in Beth’s, a wish to diminish any value or importance the intervention may have held.

For all participants, the data suggests that the ending of therapy involved powerful feelings of loss. The loss of the intervention also sits within the context of other losses already experienced, not least the *loss of the typical child*.

For clinicians too, endings are extremely difficult. Wittenberg (1999) addressed the struggle for clinicians in her paper *Ending Therapy* which pointed out how the topic is rather neglected in clinical trainings. “The reasons are not difficult to understand: the very mention of ending arouses deep anxieties” (p339-340). The research findings support the importance of parent workers grappling to keep in mind the powerful nature of loss (and endings) with parents of children with autism in their work, even if, or perhaps particularly when, parents are struggling to engage with it.

6.1.2 Impact of loss

I will now discuss the *impact of loss*, as communicated through the participants’ data. This sub-ordinate theme was present in all participants, clustered around *shock, ungrounded feelings, crazy overwhelm* and *vulnerability*.

For Christine and Amran, shock and its reverberations were evident in the data. Alongside content and delivery, something of the experience of shock was communicated physically to me in the interview which I recognised as additional validation for the theme. For Amran, the shock of the diagnosis was profound - “my child, erm, my life was completely changed” (quote 44) - and triggered a severe depression. I felt she really wanted me to understand how devastating this had been for her.

A feeling of something ungrounded could be seen in both families as the descriptions of basic foundations - sleeping, eating, washing and dressing - were not in place. For Beth, the theme cluster *crazy overwhelm* contained a lack of solidity, a sense of being tossed around, “up, up and down in waves” (quote 26). There seemed to be an idea that giving thought and attention to something could result in it spinning out of control and becoming devastating/life-threatening; the common cold becoming cancer in quote 26. Here is a reason to stay far away from reflective help (*relationship with feelings*; *desire for help*). Beth stressed that she was in an extremely vulnerable position at the time James was receiving psychotherapy. She lacked a job and financial resources, had worries about her second baby’s development and was managing all of this alone. The theme cluster *crazy overwhelm* appeared particularly significant in providing a deeper understanding of other themes in Beth’s data. As Smith *et al.* (2009) stated, “The themes are not selected purely on the basis of their prevalence within the data. Other factors, including the richness of the particular passages that highlight the themes and how the theme helps illuminate other aspects of the account, are also taken into account” (p74-5). It seems likely that at such a vulnerable period of life, self-protections would be sorely needed for survival.

Trauma and undermined parental capacities

The *impact of loss* theme in the data - shock, something ungrounded and crazily overwhelming - triangulates the views of authors who have written about the nature of the loss in parents when they have a child with a learning disability. Hollins and Sinason (2000) considered that when a disability has caused disruption to the bonding between parent and child, “the disability itself is experienced as a trauma” (p33). Fletcher’s (2004) study of 43 mothers of children with learning difficulties found that more than half continued to experience “significant difficulties resolving loss and trauma surrounding their child’s condition” (p102) a number of years post diagnosis. Both Reid and Klauber in 1999 wrote specifically about parenting a child with autism as a trauma with post-traumatic symptoms. The peer clinician also notably described her work with parents as trauma work in our discussion, adding to theme validation.

The participants’ data seemed to reflect Freud’s (1926) description of the essence of trauma, “an experience of helplessness on the part of the ego, in the face of accumulation of excitation, whether of external or internal origin” (p81). Data clustered under *unsteady foundations* particularly brought to mind the writing on how parenting children with autism can undermine fundamental parental capacities and self-worth. Alvarez and Reid (1999) described a deeply dehumanising experience of being of interest to your child only in parts, and how such an experience wears away at warmth and spontaneity.

The findings support the view that there may be danger in the traditional child psychotherapy model in this context which might be experienced as further deskilling and isolating. Klauber (1999) suggested that work with families might helpfully begin with support around parental capacities, which might be far more practical in nature than traditional child psychotherapy. Evidence for the value of this approach will be considered in *therapeutic gains*.

Rhode’s ideas on the circle of discouragement (2007a), building on Stern, Trevarthan and Alvarez’s work, are relevant to these findings on the *impact of loss*. Parents and professionals alike, repeatedly experiencing the trauma of an unresponsive child, in turn become discouraged and exhausted; no longer open to the small, sometimes tiny, moments of possibility which might occur. I will discuss the implications of the findings further when considering the *exposed and excluded* theme later in the chapter.

Maternal experience

The participants in this study were all mothers. There are many thoughts one might have about why this was the case, not least traditional gender roles in society meaning mothers often occupy the main child-rearing role. They are more likely to be involved in their child’s day-to-day activities and are more likely to be available to give time to such research activities. However it may also be that mothers are particularly invested in interventions for the child and family as they are particularly vulnerable to the impact of loss on a day-to-day basis. Research suggests that mothers experience greater stress than fathers when their child has autism (Sharpley *et al.* 1997; Seltzer *et al.* 2000). Grey (2003) found that blame for a child’s behaviour is most likely to be directed at mothers.

Further exploration of the differences between parental experiences is beyond the scope of this study. However, some consideration of maternal experience provides relevant context for the *relationship with personal capacities* theme later in the chapter.

6.1.3 Unwelcome responses to loss

Literature supports many parental reports of feeling shock, disbelief and sadness when discovering their child has a learning disability or chronic medical condition (Blacher, 1984; Bowlby, 1980; Marshak and Seligman, 1993; Waisbren, 1980). It is unsurprising that feelings of hatred, criticism, punishment and humiliation are so much harder to recognise, acknowledge or allow. Data related to *unwelcome responses to loss* can be seen in two of the participants. In family 1, the data clustered under *hatred/anger*. When Christine described how Austin tried to communicate his hateful feelings about his siblings, I saw a projection of her own very difficult feelings towards her child and his condition.

For family 3, unwanted responses are present in data related to *humiliating exposure*: "I find it embarrassing in the street" (quote 46). I recognised additional validation for this theme in my emotional response during the first contact with Amran when I telephoned her to arrange the interview. I noticed sharp feelings of embarrassment as my lack of cultural knowledge was exposed when I could not spell her surname in spite of it being a common name in her country. (I recorded this feeling in my reflective journal, bracketed it off and returned to the entry after the data analysis). Perhaps, in this moment, when the reason for my interest in her was on both of our minds, I experienced a flicker of Amran's internal experience of mothering such a child, the exposure of a felt lack or inadequacy. I wondered about understanding of ASD and possible responses towards mothers of children with disabilities in Amran's home country. I was curious about how cultural context might interact with internal experience.

As Rhode (2018) explained, parents of children with autism live with a sense of being incapable of producing a flourishing child. I thought about Singletary's (2015) description of the child's inability to make use of the growth promoting input that is available, and their parents' experience of that. Unwanted feelings can also be seen in Amran's data in the theme cluster *punishing critical voice*, when she communicated a sense of punishment from her daughter, along with her feelings of *guilt* for her resentment, "she gave me really hard time for that but of course I understand her condition" (quote 49).

Amran’s experience points to the particular nature of ambivalent feelings when a child looks typical but behaves in such an untypical way, leaving the parent (and particularly the mother) open to judgement and criticism from the general public who may not understand these invisible disabilities (rather than a more straightforward experience of sympathy which may have its own qualities and difficulties). Alvarez and Reid (1999) referred to public humiliation when considering how families with such children can become so isolated within their communities and the consequent impact on marital relationships and everyone’s mental health. For Amran, I wondered how feelings of humiliation, criticism and isolation might be compounded by the experience of being an immigrant, of already being an “outsider”.

Winnicott (1947) in his paper on *Hate in the countertransference* provided a description of the presence of normal and necessary ambivalent feelings towards the typically developing infant. How much more complicated is the situation when the child has profound difficulties? As Klauber 1999 said, “How can one admit to sometimes feeling hatred for a disabled child who looks like an angel?” (p42) For parents of children with autism, the erosion of parental capacity and self-worth and of family isolation - as well as the lack of loving feedback from the child described by Music (2009) which would, in a more ordinary parental situation, provide balance - arguably make ambivalent feelings even more powerful and frightening. It was striking that this sub-ordinate theme of *unwelcome feelings of loss* was not present in Beth’s data. Considering the dominance of the super-ordinate theme *relationship with feelings and the self* in her data, I wondered if such disturbing feelings were perhaps too far away to be visible.

The experience of presenting my findings to the regional IPA group could be viewed as validating this theme. When I described the data around criticism and hatred to the mixed discipline group, there was a question about whether I should use the word “hatred”, with suggestions for a more general and rather milder alternative. After the presentation, I thought about the disturbing nature of talking so openly about such feelings towards a vulnerable child. My own discomfort, alongside that of my peers, brought to mind Sinason’s (1986) writings on a societal death wish towards those with disabilities, which she saw as resulting from guilt about not being disabled. Sinason’s ideas on the euphemistic changes in the terminology used to label disabled people, which she saw as indicating “an unconscious effort to avoid the pain, distress and fear that disability can evoke" (Sheppard, 2019 p218), also seemed relevant.

I considered the ethics of writing about projected feelings of hatred and concluded that I wanted to do justice to the honesty and generosity of the participants by bearing the strength of the feelings communicated.

Summary - loss

Sinason recognised the significance of a "lifetime of losses" for the person with a disability (1992, p223). The phrase could also apply to their parents. The theme *experience and impact of loss* is significant for all of the participants in this study, regardless of their children's presentation. The data suggests a cumulative and current sense of loss with parents at different places in their grief process. The loss of the typical child is a trauma which has an ongoing impact on parents and relationships within the family. Ambivalent feelings towards the child are likely to be particularly complicated and frightening.

The findings suggest that parents may be in a desperate place when they first come to therapy. It is however a continual struggle to stay connected to such disturbing feelings of loss which stir up anxiety in us all. In spite of working closely with such families for 15 years, during the preparatory discussion with the peer therapist, the devastation that such parents experience had an impact on me in an almost physical way. I also felt embarrassment and shame that I had lost touch with just how bleak the experience is. Families themselves may have difficulty making contact with their feelings of loss and may be in desperate need of people who can bear their experiences with them.

Services and clinicians need to be particularly mindful of parents' sensitivities and vulnerabilities at the beginning of the work and consider the support they might offer in light of this. It is important to keep in mind the impact of losses parents will inevitably experience during their child's clinical work, such as the ending of therapy, but also the loss (exclusion) inherent in the therapeutic relationship between the child and the therapist.

6.2 Relationship with feelings and the self

“one-to-one time is great, if you could always do that”

Figure 29: Second super-ordinate theme with sub-ordinate themes

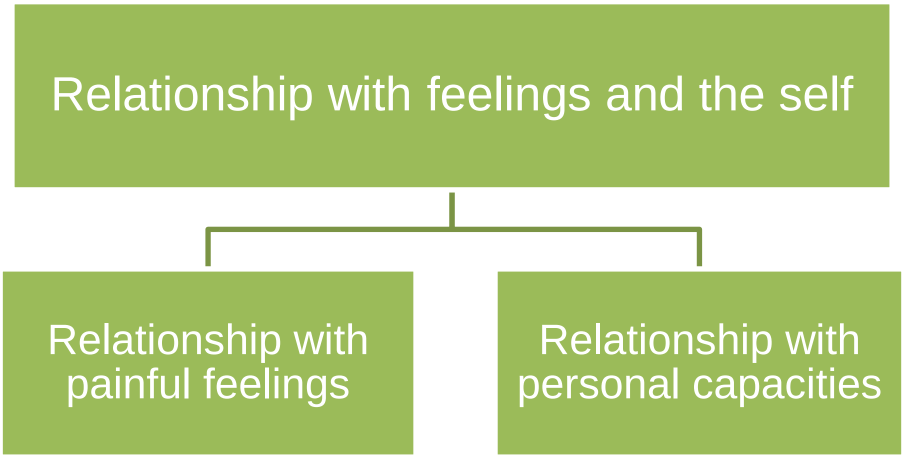


Figure 29 shows the second super-ordinate theme with two sub-ordinate themes clustered beneath it. I will describe the relevance of this theme across all participants. I will place the findings in the context of the literature and discuss any additional validation for the themes.

Thematic material came together under this super-ordinate theme which shed light on the participants’ relationships within themselves towards difficult feelings and towards their own personal capacities. The theme was present and relevant for each of the families in different ways and was particularly dominant for family 2.

6.2.1 Relationship with painful feelings

This sub-ordinate theme was present differently for each of the participants. The theme brought together data related to the participants’ internal relationships with difficult feelings. In family 1’s data, I saw an ebb and flow in the contact, a moving away and then re-connecting with strong emotions. In family 2 there seemed to be many examples of strong protective forces at work. For family 3 I noticed an absence of protective mechanisms and a pull towards feelings of loss.

Distance

Distance from painful feelings could be seen in families 1 and 2 in the theme clusters *distancing, diminishing*, *murky confusion* and *avoiding knowledge and desire.* In the analysis, I considered feelings that were “unwanted, denied and/or felt to belong to others” (Lucey *et al*., 2003 p282) as important communications which shed light on the strength of the overwhelming emotion that required such distance, for example, when Christine described her son’s hateful feelings towards a new sibling, and Beth mentioned a friend who suffered a terrible loss (quote 28). Projecting feelings in this way means they can be “thrown outside the self” and become “a matter of external perception” (Freud 1911, p64).

In Beth’s data, a need for distance was also communicated physically through the choice of interview setting. Meeting at home allowed possibilities for distraction and for physically moving away at moments in the interview. This was arguably less possible in a clinic setting. Hollway and Jefferson (2013) wrote about the significance of this form of communication, considering “what is conveyed in the less self-conscious language of bodily action” (p163).

The dominance of distance material throughout Beth’s data (the numeration for these themes totalled 194) along with its illuminating nature, pointed to its importance. I recognised a link to the *crazy overwhelm* theme discussed above and thought about the consequences of coming into contact with such feelings. As Hollway and Jefferson described, I felt the ripples of this theme “reverberate through the rest of the analysis. When interpretations do this, when they illuminate other data beyond their starting point, our faith in their robustness can increase correspondingly” (2013, p55).

Making contact with difficult feelings

Alongside evidence of distance, data related to contact with feelings was visible in families 1 and 2. Christine’s data showed her grappling with difficult feelings. She communicated this struggle through her “difficult” and “painful” relationship with the “needed” parent work (quote 7).

Beth’s moments of contact with her overwhelming, vulnerable feelings at the time of the intervention stayed with me and I noted them as powerful in my post-interview journal entry. When Beth reflected on how she might engage differently with the intervention now, I saw a moment of contact with what was not possible (*loss*) at the time, as well as a link to the next subordinate theme, *relationship with personal capacities*.

When distance is lacking

By contrast there were no occurrences of distance from painful feelings in family 3's data. For Amran, self-protections arguably failed. Amran's data revealed a preoccupation (an excess of contact) with loss both through *avoiding loss* and a *pull towards loss,* allowing her little relief from contact with painful feelings. Here the *relationship with painful feelings* theme illuminates the central nature of loss for the participant and validates the dominance of the theme *experience and impact of loss* in her data.

Different internal landscapes

The participants communicated very different ways of managing their feelings internally. I recognised these internal relationships as context for the participant's *relationship with help and change*, particularly shedding light on their use of the parent sessions.

In 1992, Alvarez proposed a "developmental view of defence". Her writing helped clinicians recognise the need to tune into the child with autism's level of functioning and make adjustments in technique in order to avoid urging them "to face their fears, their yearnings, their sadness" before they have the resources to do so (p144). The findings support the need for the same care and attention in the parent work, with help offered at a level that is accessible and manageable at that time.

6.2.2 Relationship with personal capacities

This sub-ordinate theme gathers data related to the participants feelings' about themselves, their capacities and limitations.

Guilt

All of the participants' data showed feelings of guilt. For family 1, guilt was evident in feelings of self-criticism about personal limitations and needs, in family 2 through a lack of capacity to be with her child and for family 3, the feelings were present in the strong, unwelcome feelings about her child and the condition: “I have, I have to admit to, at some points I wasn’t patient at all” (quote 45). For Beth and Amran, the theme had a low incidence of 7 and 3 respectively, however, as Smith *et al.* explained, “a very important theme, which clearly unlocks a further set of meaning for the participant, may sometimes be evidenced only once” (2009, p98).

My emotional response was significant in adding validity to this theme. When Christine replied to my question about school, I heard some annoyance in her tone, “Hmmm. As I said at the beginning, he was very withdrawn” (quote 10). In this moment, I felt I had been inadequate in my role. As Hollway and Jefferson described, all researchers inevitably make mistakes from time to time, “a clumsily worded question or tapping into unknown (and unknowable) sensitivities” (2013, p28). However, I saw this moment as more than simply a mistake. When I reflected on this experience, I considered that my strength of feeling in this moment perhaps communicated something of Christine’s experience of an internal critical voice.

Inadequacies and damage

I thought about feelings of self-blame that parents - and particularly mothers who physically grow the baby inside themselves - may hold when their child does not develop typically, even if they are also able to recognise the contrary. Anderson and Eifert (1989) found that women are more likely than men are to blame themselves when a child has a disability. Beth’s firm statement, “I don’t think I did anything wrong in my pregnancy” (quote 28) led me to wonder if this feeling was being said to another part of herself. The material clustered under *fear of causing damage* in the data of family 2 seemed to contain an idea of a very powerful internal concern about causing harm. The content in this theme cluster included anxiety about saying something which could result in the withdrawal of psychotherapy for other parents, along with an idea of a highly damaging intervention, “as long as people weren’t trying to give him electric shocks or something (laugh)” (quote 34). I saw a link to the theme cluster *crazy overwhelm*. Both theme clusters had significance in my mind due to the power of the material.

Internal feelings of guilt about personal inadequacies inevitably and painfully sit within an external context of maternal blame. Historically this view was expressed by Bettelheim (1967). Currently, mothers are likely to have regular experiences of a judgemental public gaze when their typical-looking child behaves bizarrely.

Hatred and guilt

Klauber (1999) described the guilt parents can feel about their feelings of hatred towards their child and the disability: "What is often so hidden within the submission to the tyrannical demands, is guilt about hatred of the disability and of the child herself" (1999, p42). Simpson and Miller (2004) recognised how overwhelming feelings of guilt may impact on the parent's ability to see the child and their difficulties clearly. Here is a link to the *murky confusion* cluster and data about not being able to see: "I just brought her here blindly" (Amran, quote 43).

Rhode's work on the circle of discouragement (2007a) described a difficulty seeing and responding to minimal cues from the child (and vice versa) in the context of overwhelming parental feelings. In my work as a music therapist in a special school, before training as a child psychotherapist, I recognised this difficulty over many years of working with families of children with severe autism who were non-verbal. In response, the school enabled me to develop a model of group family music therapy. Three mother/child dyads attended a weekly music session where parents were encouraged and supported to improvise in response to their child's vocalisation, movements or music making. The dyads were supported by a co-therapist and their music was held within a whole musical structure from the piano. The work aimed to notice, support and encourage those brief possibilities for connection, when a risk was taken by either parent or child in reaching out or responding to the other. The musical session was followed by a talking time for the parents alone; an opportunity, often taken, to voice unwelcome thoughts and feelings in a safe environment. These closed groups sometimes ran for a number of years, with parents extremely committed to the work (Bull, 2008).

Different states of mind

The data clustered under *personal capacities* (family 2) suggested a more kindly voice, an awareness of what might or might not be possible at different times of life, in different states of mind. Beth's comments about how therapeutic support for her son (and herself) might feel very different now seemed to include an idea that her relationship with the intervention was in the context of a deeply internal relationship with feelings and herself: "I do think if I had it now it would probably be a very different experience (pause).Tricky one isn't it? Yeah, and it is a very, very, it's a very personal thing" (quote 35).

Summary - relationship with feelings and the self

The data in the study showed parents to be at very different places in their relationship to difficult feelings: needing distance; moving in and out of contact; and devastating overwhelm. Feelings of guilt were present in all three families and the theme was triangulated by the literature.

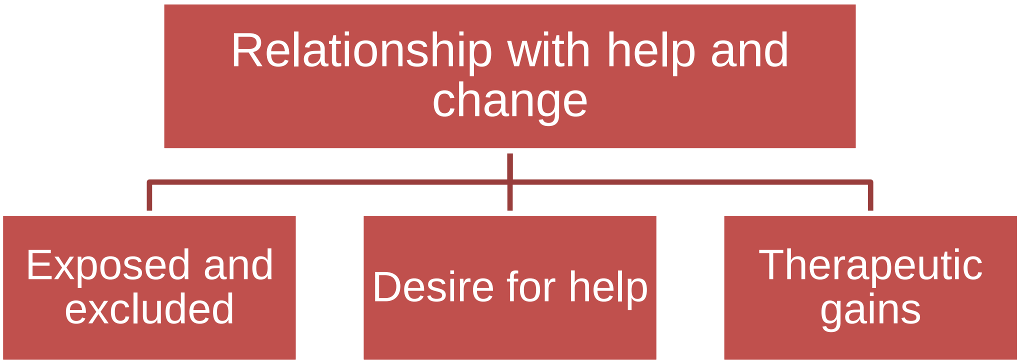
The analysis of the data involved a consideration of the researcher's emotional response. Arguably this allowed for a "deeper exploration of the respondent's experience, including areas of internal experience" (Donaghy, 2017 p224). Such emotional responses are part of "feeling with research participants" which Hollway and Jefferson argued is essential in ethical research (2013, p164).

A parent's internal world, how they manage feelings and their relationship with their own capacities is the context for how they engage with and view the therapy and the possibility of change in their child. Child psychotherapy, with its focus on the patient's level of functioning, is arguably well placed to assess and meet the whole family at whatever level support can be accessed.

6.3 Relationship with help and change

"I kind of (pause) was happy for it to be a little bit (pause) murky"

Figure 30: Third super-ordinate theme with sub-ordinate themes



I will now discuss the theme *relationship with help and change* in relation to the literature. The theme brings together data concerning the participants' relationship with the intervention. I will consider how the data links to what the participants' have communicated about their internal relationship with help. I will describe how the participants' relationship with the research adds validation to the theme.

This super-ordinate theme is particularly significant for family 1 due to the role it plays in understanding the participant's other data. This section concludes with a consideration of *therapeutic gains* which has relevance for all participants.

6.3.1 Exposed and excluded

Data from family 1 and 2 led to a sub-ordinate theme of *exposed and excluded* which brought together ambivalent feelings about involvement with the intervention and help, such as feeling rejected, critical towards, exposed by and excluded from the work. This sub-ordinate theme was not present in family 3.

Exposure and judgement

For Christine, the data suggested feelings of *exposure*. For Beth, there was an idea of a critical other: "I wonder why they've picked me?" (quote 37) For both participants, there seemed to be concern about what the clinicians might notice. Additional validation for the *exposed* theme is present in the way families 1 and 2 related to involvement in the research. Both participants mentioned information visible to me outside of the interview setting. I noticed some discomfort in their comments, "you'll probably be able to read about it" (family 1, line 338) and "you've probably got it on your record somewhere" (family 2, quote 27) (see Informed consent in practice, p68).

The findings suggest that parents can feel that their perceived inadequacies are on show to the world when they engage in psychotherapy. As Klauber (1999) noted, parents seeking help from professionals face "a minefield filled with the fear of judgement and criticism, compounded by the dreadful stirrings of the memory of noticing something was wrong" (p36). There is a strong link to *relationship with personal capacities* and feelings of guilt, with a concern that close attention will confirm internal fears about self blame and damage. Such fears of judgement link back to Bettelheim's (1967) critical writings about mothers.

Excluded and rejected

For both family 1 and 2 there was a theme of feeling *excluded* from the psychotherapy work with their child. In quote 12, when Christine described the strong bond that Austin made with his therapist Mary, she communicated painful feelings of exclusion and a difficulty with feeling in the dark. For Beth, there was an experience of not being invited in, which I felt contained a feeling of rejection.

I began to consider the particular nature of a mother's experience of being on the outside of a therapeutic relationship when she has a child with autism. In this circumstance, it is unlikely that the primary bond has developed as hoped. How devastating might it feel to witness a growing relationship between your child and their therapist if your own experience has been so disconnected and remote, however grateful and relieved you also feel that such a relationship is possible? I identified pain in Christine's comments: "I kind of understood him but his communication was so poor and, and indirect that it really sort of took some, you know quite a skilled person to, to, to, to get through to him" (quote 1). Again there is a link to feelings of self-criticism and guilt alongside perhaps a kinder internal voice which recognises that the therapeutic situation is so different to the incessant de-humanising nature of a parent's experience (Alvarez and Reid, 1999).

Both Christine's dominant theme cluster *scepticism/disbelief/ambivalence* towards the intervention, and her acceptance of therapy with Austin as something "murky", could be seen to triangulate the *exposed and excluded* and *guilt* themes. The *murky confusion* cluster also communicates trust in the process alongside perhaps some investment in therapy remaining unclear.

When ambivalent feelings are lacking

The data of family 3 strikingly does not include feelings of exposure and exclusion in relation to psychotherapy (feelings of *humiliating exposure* are present in relation to the child's autism, such as those seen in quote 46 when Amran describes her experience in the street). As will be discussed under *therapeutic gains*, Amran communicated her experience of the intervention as something life-giving and crucial. In this context, I wondered if the intervention and the clinicians needed to be kept safely in a "good" place in her mind, with any ambivalent feelings kept far away. Klein (1946) wrote about this concept of splitting as a fundamental mechanism in human psychic life. Here, “what is left unsaid may be as significant as what is said in the lived experience of the participant” (McGregor Hepburn, 2018 p60).

Alongside this interpretation, it is worth considering Amran’s very different feeling in relation to the work with her daughter. There is a strong sense of something “integrated” (quote 50) and linked up in her experience. Material related to this is included under the theme cluster *understanding beyond words* (*therapeutic gains*). She described receiving frequent feedback from the therapist after Jemima’s session, “so I wasn’t in darkness, on the contrary” (line 282). I wondered if Amran had, in external reality, been more included in the work, perhaps in response to both her depressed state and her daughter’s more severe, non-verbal presentation. This may be an additional explanation for the absence of excluded feelings in relation to the intervention.

When a child can not choose to tell

Both parents in families 1 and 2 described how their children were unable to tell them about their experience of therapy due to their age and language capacity at the time of the work. It is significant that this appeared to add to the parents’ feelings of exclusion from the work, perhaps compounding an experience of exclusion from their child’s world in general. A verbal child may of course choose to keep the contents of their therapy to themselves. For a non-verbal child and one who has problems with communication, there is no choice. This may be a further consideration for a flexible approach to the work.

When a child is non-verbal or non-communicative, the therapist may need to be more proactive. As Rhode (2007a) pointed out, it can be extremely hard for parents of children with autism to tune into and hold on to the potential for change in their child. In this context, there may be significant benefit in parents hearing about small changes within sessions so that the possibility for realistic hope might begin to develop. Without this there is a danger that parents will see little value in the process and reject the work.

Literature on including parents in therapeutic work

These findings support the literature on parental experiences of psychotherapy. In 1999, Reid proposed an extended assessment which would include the parents in the room in order not to widen the gulf between parent and child, to support communication between them and also for the therapist to avoid becoming a kind of expert and in the process, further diminish parental capacity. As Reid argued, if the aim is communication, “it is counter-productive with most families to take the child away to another room for assessment” (1999a, p19).

Urwin recognised the need to include parents in the work. In 2007, she described the value of the feedback meeting during the assessment, as therapist and parents share their experiences of the child and build a relationship, “enabling them to sustain commitment to a lengthy and difficult treatment” (2007a, p136). In 2011, Urwin argued for constructive ways of involving parents, so that they become intrinsic in evaluating their child’s progress in the therapy.

The study findings suggest that it may simply be too difficult for some parents to be on the outside of therapy. Services may need to keep this mind when considering why psychotherapy could be rejected by some families. A flexible approach to include parents in the work may be indicated, particularly at the beginning. Houzel (1999) and Rhode’s (2018) work on therapeutic observation is highly relevant here as attention is given to the parents and child together, with a focus on the dance between them.

6.3.2

Desire for help

The second sub-ordinate theme *desire for help* held significance for all three participants. The theme brought together data related to the participants’ internal desire for help and change. Communicated feelings about the intervention are considered in the context of the participants’ *relationships with feelings and the self*. Data related to the parent sessions were particularly relevant to this theme.

Significance of the theme across participants

For family 1, a crucial theme cluster *overcoming* developed which was particularly evident through the participant’s delivery. This theme held particular importance as it shed light on how, in spite of significant data revealing *scepticism/disbelief/ambivalence* towards the intervention (perhaps arising from self critical/guilt feelings), Christine was able to make use the intervention for herself and her family, leading to a substantial experience of *therapeutic gains*.

Previous experiences and internal resources naturally mean that people relate to help in very different ways. For family 2, a theme cluster developed around a *disappointing, demanding other* in relation to help. The data suggested that support was not felt to be helpful, but rather draining and demanding. In this context then, and bearing in mind the dominance of material related to *avoiding knowledge and desire, diminishing, distancing,* it is unsurprising that there is no **desire** for help visible in Beth's data and the intervention is described as something which has no great significance.

In contrast though, Beth describes her strong commitment to the work, taking her son to sessions three times each week: "I felt I had to do it, I kind of knew I had to do it" (quote 41). In spite of her apparent indifference, there seemed to be an idea of something valuable that she had to find a way to manage for her child. Alongside this more helpful view of the intervention, it is important to keep in mind that Beth also communicated a need to provide everything possible for her son: "I was basically putting my hand up to take whatever I could" (line 84). I wondered about the significance of the *guilt* and *fear of causing damage* themes for parents of children with autism and a possible need to compensate by engaging in every possible intervention in response to strong critical internal feelings.

For family 3, data related to feelings about the psychotherapy are also complex in nature. Amran communicated an eager desire for help. She explained how Jemima "immediately rushed to the door and waited and she was eager to go with her" (quote 48) which seemed to contain something of her own feelings. Negative feelings about the intervention are communicated only in reference to endings of the work. Amran's hugely positive feelings are of course valid and understandable due to her desperate need for help at the time of the work. However, the lack of ordinary ambivalent feelings and thoughts about splitting described above, provide relevant context which should be kept in mind. Ordinary critical feelings about the intervention may not be accessible to this participant at this time.

Desire for help and the research relationship

I considered that at times the way the participants related to me in the research interview provided additional evidence in support of the themes. For this theme in particular, I was curious about the participants' motivation for engaging in the research. At the beginning of the interview with family 1, Christine asked if Lisa, her parent worker, was my supervisor. She told me that she completely trusted Lisa and I felt in this moment I was experienced as a link to something and someone she had found incredibly helpful. I saw validation for the theme *overcoming* as Christine moved beyond feelings of exposure in talking to me, perhaps due to a desire for a link to something helpful, and also due to gratitude for the help received. At the beginning of her interview, Beth asked me if I was a child psychotherapist. Although Beth appeared to avoid desire for help, again I felt I was perhaps a link to something she was wondering about accessing again (*hopeful wonderings*). At the close of the interview with family 3, Amran asked if we would meet again and expressed disappointment when I reminded her that we would not. I felt Amran had found the interview helpful and wanted more. Here was validation for her eager desire for help as well as the dominance in her data of a difficulty with endings and loss.

Desire for help and parent work

The participants' relationship with help is hugely significant to their relationship with the parent work that ran concurrently to the child's therapy. Christine, perhaps as a result of overcoming, was "very involved" in something she saw as "incredibly important (stressed)". Similarly, for family 3, the sessions were described as extremely valuable. In Beth's data, there is a different feeling, one of *anger with connecting*. Beth decided to stop attending parent sessions: "It suited me more to use the sessions just to sit in reception" (quote 28). Her material relating to a disappointing, demanding other is highly relevant here. I also wondered about a connection to the *fear of damage* and a *crazy overwhelm* theme; whether the parent work at that time might contain something of the powerful electric shock she mentioned in quote 34.

There is agreement among psychoanalytic writers about the crucial nature of work with parents when families have a child with autism. The peer clinician also stressed her view that in all therapy parent work is important, but in this field it is essential. The purpose and value of the parent work will be considered alongside the participant data in the following section, *therapeutic gains*.

6.3.3 Therapeutic gains

This final sub-ordinate theme brings together data related to the gains the participants identified from involvement in the intervention, for themselves and their child. It was present in all of the family's material through theme clusters such as the *crucial importance of help*, *understanding*, *gratitude*, *joy* and *hopeful wonderings*.

Crucial, life-giving help

For families 1 and 3, data shows the intervention experienced as something crucial and life-giving. In family 1, theme content was supported by religious language. For family 3, the data communicated an idea of drip feeding, a slow return to health and establishing of foundations, "it was very slow, but I felt relieved after each session" (quote 52). I saw additional validation for this theme in my post-interview reflections when I noted how slowly and carefully Amran read the documents relating to the research, as well as her strikingly slow and steady way of speaking throughout. The experience for both participants seemed to be one of crucial help being provided at a desperate and traumatic time.

Parent work and trauma

The participant data on *experience and impact of loss* supports the role of parent work in processing trauma for these families. As Amran explained, "the crying that I had after the diagnosis was unbearable ... but it helped me a lot in releasing lots of things inside me" (quote 52). Klauber (1999) explained how parent work provides a place to work through and move on, so that the child can be seen more clearly. In the peer discussion, the therapist also spoke about parent work as trauma work, so that reality can slowly be faced.

Establishing foundations - supporting parental capacity

Bearing in mind how traumatised parents can be at the start of the work, Klauber (1999) suggested beginning with practical help around eating, sleep patterns and toileting in order to restore confidence in the parenting role. Two of the participants refer to this kind of help, providing validation for Klauber's proposition. In the case of family 2, Beth described an absence of practical help and a reason for parent work feeling like the wrong kind of help for her at this moment in her life: "You know, I, I felt

I needed concrete help" (line 649). For Amran, the "advice" that she received from the therapist and parent worker about how to tackle some situations that she faced with her daughter was part of the life-giving support she felt she received.

Establishing foundations - Intensive psychotherapy

For all the families, there is evidence to suggest that the intensive nature of the intervention was helpful. Christine commented, "the fact that we were getting, we were getting three sessions a week seemed to me to be key" (line 554). Here was an idea of receiving something substantial. When I asked Amran about her experience of the parent sessions she told me "I had three, the same as Jemima" (line 304). She clarified that she was talking about seeing three different clinicians over the course of their time at the clinic, however my association in the moment was that she had, like her daughter, received three sessions per week. I recognised her intense need for help and something about the value of the structure of the sessions when life felt so desolate. Beth also mentioned an appreciation of structure in her thoughts about how her son developed: "I think the schooling and the structure and all that kind of thing helps" (quote 40). I felt this comment contained a reference to the three sessions each week and also communicated the need for distance. Alvarez (1992) referred to the regularity and reliability of the setting, along with the structure inherent in the psychoanalytic technique, as providing "an opportunity for structure and order to begin to develop in the child's mind" (p4). The findings suggest that the intensive nature of the session may also support recovery in the parents.

Understanding the parents

Families 1 and 3 spoke about the value of the intervention, the parent work, for themselves. For Amran, it was a place to bring her grief: "I do remember that she just let me talk. I talked a lot and I (laugh) cried a lot" (line 372). This brought to mind the parent worker's aim to be truly open to "how it feels" (Urwin, 2011). Christine described the sessions as her psychotherapy and explained how much she gained from the process: "it gave me a huge (stressed) insight into myself that I, you know I'd never sort of had before" (quote 9).

My discussion with the peer therapist supported these findings about a parent's need to use sessions as a place for themselves as individuals, not only as parents. She spoke about the parents she works with using the space to understand their relationships and internal worlds; to regain contact with their own lives and who they were before they became a parent. Klauber (1999) also noted that parents used the sessions to make links with their own history and their internal worlds.

Understanding the child

Christine described how her experience of the sessions with Lisa helped her to see the value of the work for her son, recognising how personal the relationship is, “only he knows what he got from his psychotherapy in the way that only I know what I got” (quote 18). Zimmermann (2017), when writing about hermeneutics, described the importance of resonance in our lives for understanding to occur. This resonance can be seen through Christine’s choice of language, the echo of developing “**insight** into myself” and her feeling that Lisa had a “real **insight**” into Austin.

Reid (1999a) hoped that as parents felt understood and contained in their sessions, they might also become more open to the thinking of the clinician. For Amran, the material clustered under *understanding beyond words* supports this idea as she repeatedly described being able to see/sense/feel the progress in her child, after the blind, unseeing material from before the intervention began. I thought about Tustin’s (1981) description of the therapist lending their “thinkings”, having imagination for two until parents are in place to begin to see their child more clearly for themselves.

As parents feel understood in their own right and begin to understand their child through the parent work, there is hope for a weakening of the “bad internal voice” (Tischler, 1979). Rhode (2018) stressed the importance of the parent work for both the child and the parents in this regard, in helping parents to understand that the child’s internal parents differ from the reality of its external ones.

The crucial nature of understanding as a *therapeutic gain* was communicated particularly strongly in Christine’s data. She movingly stressed how significant gaining an understanding of her child was for her and her husband. “I think that we felt we would never know him properly” and then “I think we pretty much feel that we do now” (quote 21). Through the psychotherapy, Christine came to understand that Austin had feelings “in absolute spades” (quote 21) rather than not experiencing them at all. Rhode (2012) referred to this problem for parents of children with autism where, “A child who does not exhibit certain behaviours can easily – and quite reasonably – be thought to be incapable of them” (p109). This difficulty is at the core of Rhode’s work on the circle of discouragement (2007a). Singletary (2015) also highlighted the nature of helping parents of a child with autism to understand their internal world, explaining how this leads to the child feeling less stressed and anxious. Urwin (2011) described how all children with autism, to some degree, benefit from being understood.

As the parents became more aware of their child's inner world, so their perceptions of their child changed: "Jemima became a different person from when she was three-year-old" (Amran, quote 53). Changes in parental perception have been recognised as crucial for development in the parent-child relationship. "Progress can result from parents realigning their understanding, and increasing attunement with their child" (Delahunty *et al*., 2018 p165). Such changes in perception are the focus of the Sheffield Learning Disabilities Outcome Measure (SLDOM), a tool that aims to measure internal factors in the parent/carer in relation to having a child with a learning difficulty as well as external factors: the context and environment surrounding the child. Delahunty *et al*.'s (2018) analysis of the tool found that parental perceptions were complex to measure quantitatively. For example, it is possible for the scale to show no change, or indeed worse scores of self-rated understanding, as parents become more realistic about their child. Here is support for the complexity of parental views of interventions and development in their children.

Integrated development and healing

Both Christine and Amran clearly recognised changes in themselves a result of the parent work and saw these developments as significant in their feelings about the intervention's efficacy. Both participants' data also included views on the intervention as significant for their child in its own right and recognised substantial development in their children as a consequence.

As Rhode's (2007a) circle of discouragement suggests, parent and child are intertwined and do not exist in isolation. Alvarez (1992) wrote about the concept of a "double helix" when considering the role of heredity and environment in developing autistic symptoms. A similar idea seems relevant for recovery, with progress in parent and child, twisting "around each other in interacting spirals" (p187-8).

For Beth, who did not engage significantly in the parent work, data related to *therapeutic gains* is much less apparent. Beth perhaps stayed away from any strong positive feeling about the intervention but did reflect on its contribution to James's overall progress at the time. This finding suggests there may be value in working solely with the child if parent work is not possible.

Hope, relief, joy and gratitude

Positive feelings about the intervention were present in all participants' data through *hope, relief, gratitude* and *joy*.

For Beth, positive feelings were evident through her hopeful wonderings about whether to engage in the intervention again in the future. Data under this theme revealed a general feeling of a positive experience of the work alongside an awareness of a limit of what was possible for her at the time (*relationship with feelings and the self*). Hope and relief were also visible in the data of the other two participants. As Amran explained, “it was the first time I could see Jemima doing something useful” (quote 54).

The development of hope in the parents during the intervention (as opposed to loss of hope seen before it began) has real significance for a child's development. Klauber (1999) described how the parent worker helps the parent to recognise real signs of hope when parents are not in a place to see them. Rhode described the importance of hope, seeing parental expectations as crucial in a child's language development (2007a). The findings could be seen to support Rhode's ideas. All of the families mentioned improvement in language and understanding in their child over the course of their psychotherapy, “his language just improved so much” (Christine, line 104). Rhode and Urwin wrote about the development of language in the struggle to become a separate person, as the child finds “a voice of their own” (Rhode, 1999 p80).

For families 1 and 3, there were feelings of relief at a reduction in disturbing behaviours (Austin stopped chewing his bed, Jemima was no longer dropping to the floor in the street). Relief was also visible through recognition of their child's ability to build relationships: “I could understand that Jemima has feeling towards people, not just me or her Dad” (Amran, line 253). Christine spoke about Austin's gained capacity to express his emotions and write: “I think of it as being a very un-autistic thing to do” (quote 22). Alvarez and Reid (1999) noted the relief parents feel in seeing “a more robust and ordinary part of their children's personal personality hidden among the symptoms” (p9). Both Alvarez (1992) and Urwin (2011) recognised the importance of clinicians supporting the non-autistic parts of the child's personality in the work.

Joy and gratitude

The findings suggest that a highly significant change for two of the participants was an ability to find joy in the child and connect to loving feelings, “he’s amazing, he’s doing amazing things” (family 1, quote 22). Here the parent work may have served to enliven the child in the parents’ minds. Such feelings hugely mitigate the unwanted feelings of loss, connecting to the data around *relief.* There developed a theme of *gratitude* which gained validity through my emotional response in the research interview. When Amran read the documents carefully at the beginning of the session, I noted feeling gratitude for the careful attention she gave my work. For Amran and Christine, their response to me as a link to the intervention was also significant. When Amran became stuck and Christine lost clarity or focus, I noticed gratitude towards me when a brief comment helped them to make a link in their minds to something helpful; they could gather themselves and move on. Interestingly, all three participants apologised for talking a lot at the end of the interview. I wondered about a feeling of something too much and gratitude for someone who was interested in knowing “how it feels” (Urwin, 2011). I recognised how this relationship with me in the research interview provided additional validation for the value of the parent work in the participants’ data.

Beth expressed gratitude for the “whole package” that her child received. The data under the *hopeful wonderings* theme, recommendations of psychotherapy to other parents, as well as reflections on early intervention, all added validation to a positive experience of the intervention within the context of a complex relationship with the help, “that’s one thing I do believe is that intervention and early intervention can make a huge difference” (line 627).

Psychotherapy inevitably sits within a package of interventions for the child and family. Christine as well as Beth referred to a difficulty really knowing what had made the difference for their child (*scepticism)*. Urwin (2007a) explained the importance of the concurrent interventions for family and child. Richardson (2003) stressed the need for good communication in order to create an environment conducive for the child’s development. The findings support the value of joined up thinking in the network. Child psychotherapists might play a significant role in increasing understanding in the whole environment, as well as learning from the different perspectives of their colleagues.

Summary - relationship with help and change

Parents with children with autism can feel exposed and excluded by the work. Clinicians need to hold this in mind and consider working in flexible ways to help families to engage. It may be too much to expect some parents to manage the traditional model of being outside the room, particularly at the start of the work.

A parent’s internal relationship with help and change is the context for how they relate to the intervention. The relationship is likely to be complex. Parents will be at different places in relation to help, resulting in the possibility of different degrees of involvement. They may need a more practical kind of help at the start of the work with a focus on supporting parental capacities. The data all points to the need for flexibility and meeting the parent where they are. Psychotherapy is arguably well suited to this task as a patient-led intervention.

Parents as well as the children seemed to benefit from the intensive nature of the intervention. Parent work is often crucial to the process of development in the family but there may be value in proceeding even when it is not possible.

All of the participants communicated benefit from the intervention and gratitude for the help. The findings show that the parents have some faith in the psychotherapy process that perhaps comes from enlivening the child in their minds with a renewed capacity for enjoyment and love.

Conclusions

In this chapter, I have placed the research findings in context by discussing how the themes which emerged relate to relevant literature. During the data analysis stage of the project, supervision and peer reflection provided triangulation as the themes developed. Theme validity and reliability have been further addressed in this chapter by discussing internal validation (links between themes) and by drawing on material from the peer interview and reflective journal. These additional methods of research triangulation were used to provide robust confirmation of the method and themes.

In the following chapter, I will summarise the findings and then evaluate the study by reflecting on the process of conducting the research. I will explore the limitations of the study which have become visible through this discussion. I will consider from this retrospective position additional possibilities for context for the research findings which may have further addressed theme reliability and validity and thus strengthened the research. I will then consider how these reflections might usefully inform future studies.

Chapter 7 Summary, recommendations, evaluation and conclusions

In this chapter I will summarise the key findings from the research and outline recommendations for improving practice. I will then evaluate the study and suggest ideas for future research. I will conclude with some final reflections on the research experience.

7.1 Summary of findings

The three participants' experiences of child psychotherapy led to the following findings. Any general statements are presented with necessary caution.

1. **Parents of children with autism can experience a powerful sense of loss. Parents may begin therapeutic work in the midst of a cumulative and current trauma**

There were powerful communications of loss from all the participants, across all presentations of symptoms of autism. Every parent stressed the desperate state they were in before the work began. This finding supports Alvarez and Reid's (1999) thoughts on the dehumanising nature of parenting such children, as well as Reid and Klauber's (1999) recognition of the experience as a trauma.

Living with trauma can have a significant impact on a parent's ongoing relationship with their child. In such a state, it becomes extremely hard for parents to see their child clearly. There is little room for realistic hope. Rhode's (2007a) ideas on the circle of discouragement are very relevant here.

Ambivalent feelings towards the child and the condition are likely to be particularly complicated and frightening. Klauber (1999) described the strength of such feelings and there are links to Music's (2009) writings on neurobiology and the possible lack of loving feedback from such children.

2. **Parents' relationship with child psychotherapy is likely to be complex**

Parents will be in different places internally in relation to their grief process and their feelings about themselves. A capacity to engage with help and subsequent views on the intervention sit within this context. Such complexity means that views of the intervention can change with different states of mind.

The traditional psychotherapy model could easily feel exposing, critical and excluding for parents. These findings support Klauber's (1999) writing on parental experiences of engaging with clinicians.

3. Parents communicated that the help they and their child received from the intervention led to an improved quality of life

All of the families communicated benefit from the intervention. All saw value in intensive psychotherapy sessions, which may have been helpful for parent and child alike, providing a substantial, steadying support. This finding concurs with Alvarez's (1992) thoughts about the importance of structure in psychotherapy in supporting development.

Where engagement with parent work was possible, participants described considerable personal benefit, enabling trauma to be processed and the development of understanding of both themselves and their child. An appreciation of the value of the intervention for their child appeared to stem from their personal experience of the parent work. This finding validates Klauber's (1999) description of the value of parent work as a place to process trauma and as an important intervention for parents in their own right. This finding also suggests that development and recovery in parent and child is intertwined, as outlined by Rhode (2007a, 2012, 2018). However, should parent work be untenable, there could be value in working solely with the child.

Developing an understanding of the child is a stated aim for psychological interventions in current NICE guidelines (2013). The finding adds support to the argument for psychotherapy as an appropriate intervention for this client group. This is consolidated by Singletary's (2015) views on the importance of psychotherapy in providing understanding of the child's inner world.

Two parents saw significant development in their child as a result of the psychotherapy, which could be viewed as a strengthening in the non-autistic parts of the personality (Alvarez, 1992 and Urwin, 2011). They described a reduction in anxiety and stressful behaviours; development in language and communication; greater capacity for emotional expression; and development of their child's capacity to build relationships. A significant gain seemed to be a change in parental perceptions and reconnection to loving feelings, resulting in enjoyment of their child. Psychotherapy can be seen here to increase a sense of connection and decrease experience of stress, which were stated aims of treatment in Singletary's (2015) review.

Child psychotherapy sits within the context of a web of multiagency support. Two of the families referred to the intervention within this context and expressed appreciation and gratitude for the whole package. Richardson *et al.* (2003) and Urwin (2007a, 2011) stressed the importance of psychotherapy's place within a supportive environment surrounding the child and family. The finding supports the idea of the integrated clinician as part of a network where learning can take place through differing perspectives.

7.2 Recommendations

The recommendations that follow from the findings concern the child psychotherapy profession and also the multidisciplinary services that provide interventions for families of children with autism.

1. <u>Support clinicians to work with loss</u>

<u>Parents' traumatised state at the beginning of work</u>

Services and clinicians need to pay attention to parents' sensitivities and vulnerabilities at the beginning of the work and consider the support they might offer in light of this**.** The findings support the value of a multidisciplinary team approach that can offer different kinds of interventions to meet families' needs and capacities at different stages in their journey.

<u>Staying connected to loss</u>

Parents may be in desperate need of people who can bear their experience with them. It is hard for clinicians to connect - and stay connected - to the devastation of loss and its ongoing nature in families of children with autism. Wittenberg wrote about the therapists' struggle with loss in her 1999 paper on ending therapy.

There is a need for adequate supervision for child psychotherapists undertaking work with the child and with their parents. Clinicians should be mindful of the impact of the losses parents will inevitably experience during their child's clinical work such as endings, but also the loss (exclusion) inherent in the therapeutic relationship between the child and the therapist.

Child psychotherapists may be well placed to provide supervision to other members of the multidisciplinary team as they engage with loss.

2. Consider both parent and child

Careful assessment

The findings suggest that child psychotherapy could feel excluding and persecutory for parents at the beginning of the work. Careful assessment is indicated to consider what is manageable, as proposed by Reid in 1999.

Different parents require different kinds of support (Fletcher, 2004). As parent and child development is intertwined, clinicians should give consideration to parents' internal worlds and functioning with the same care and attention they give to the child. Help should be offered in a way that is accessible and manageable. A slow and steady approach, beginning with practical help, may be valuable. Klauber (1999) suggested this could help to support parental capacities.

Including parents

The findings support the need for flexible approaches to the traditional child psychotherapy model. Including parents in the work, either in sessions for parent and child together or by providing more regular feedback may be indicated. Without this, parents may reject the work. Urwin (2007a, 2011) stressed the need to include parents in the work, making them central to evaluating progress in their child. The findings support Rhode's work on therapeutic observation (2018).

3. Consider the complexity of views

As parents' relationship with psychotherapy is likely to be complex, there could be a danger in using outcome measures that are not sufficiently sophisticated. Clinics should bear this in mind when assessing parental views and use measures which are sensitive to such complexity.

4. Raising the profile of the work

With parents

As Drucker (2009) explained, parents can be presented with a bewildering range of possible interventions and are asked to make critical decisions about who will work with their child and how. The findings suggest that parents, in their traumatised state, rely heavily on advice from others about whether to engage in psychotherapy. It may be helpful for clinics to consider ways for prospective parents to hear from families who have been through psychotherapy, perhaps through discussion groups or by facilitating telephone conversations.

Within the discipline

There continues to be a lack of knowledge and understanding about what child psychotherapy can offer this population. As Rhode (2018) explained, many clinicians remain unaware of the development of research into the neuroplasticity of the brain (Singletary, 2015). There is an ongoing need to raise the profile of the work within the discipline. This may be a suitable focus for the Association of Child Psychotherapists' (ACP) Supported Clinical Network for clinicians working with children with autism once it has become established.

Within provision at large

It is all too easy for child mental health services to reject referrals concerning children with autism, particularly in a climate where services are under too much pressure, as can currently be seen in CAMHS. However, the affects of the symptoms of autism on the family are extremely costly to the NHS. A treatment which improves quality of life across the family arguably offers value for money. Drucker (2009) explained that, when families are deprived of the intervention, parents are deprived of valuable support and understanding about their children. The children are then doubly deprived of their parents' understanding as well as the therapist's capacity to understand their inner world.

Clinicians could help by prioritising communication about their cases with others in the network, through discussions, letter writing and presentations. The benefits of this are two-fold. Firstly they will aid understanding (as well as learn from others) about particular children in their network, thus fulfilling the NICE (2013) guidelines on increasing carers' and teachers' understanding of the child. Secondly, the benefit and value of child psychotherapy for families of children with autism will be more visible within the wider network.

7.3 Study limitations

I will now evaluate the research through a consideration of study limitations.

Fathers

The research question was concerned with the views of parents. The participants in this study are all mothers who are primary carers. During the research preparation, I decided to focus on the views of parents who had attended the parent work sessions. The two fathers in the research families appeared to be in a secondary care role and neither had been regular attendees of the parent work. Similarly, in practice, only mothers volunteered themselves for the research interviews. In the UK, far fewer fathers are primary carers. They are also less likely to be involved in regular parent sessions in psychotherapy. The lack of paternal voice in the research is a consequence of the rarity of the phenomenon under investigation.

As the parent typically less involved in the sessions personally, a father's (or any secondary parent's) view might add valuable insight into perspectives of the intervention without direct personal gain. I am also curious whether such views of the work would offer insight into the impact of the therapy on the whole family. Gathering views of fathers (or secondary parents), and perhaps both parents in a family where they are present, could be kept in mind for future research.

Although the lack of a father's perspective is a limitation of this study, there may have been benefits in allowing a deeper exploration of maternal, primary carer views of the intervention as the participants were a more homogeneous sample.

Length of follow up

The participant criteria stated that, to be eligible for inclusion, families were required to be a minimum of six months and maximum of seven years from the end of therapy at the point of interview (follow up). Families 1 and 3 were one year, four months and one year, five months post therapy respectively. Family 2 was interviewed three years, eight months post therapy. Although this was well within the inclusion time frame, in practice the distance from the work caused some frustration in the participant as it was hard for her to recall detail (this external difficulty sits alongside the role of *distancing* in the data). Beth felt she would have had more to say had she been interviewed closer to the ending of the work with James.

With the retrospective question in mind, it would have been interesting to have heard the views of a parent at the maximum distance of seven years from the therapy, alongside those at a closer and middling distance, in order to understand more about how participants remembered their experience and how views might change over time.

Differences in therapeutic provision

I learnt during the interviews that there were a number of differences in the parameters around treatment experienced by the families. For example, in family 1, Austin had begun weekly psychotherapy away from the clinic, in the family's new location. This was ongoing. In family 3, Amran mentioned that both she and Jemima had had a number of changes of therapist and parent worker over the course of their work. I wondered about the impact of these losses on the work and Amran's view of it. I was not aware of the other families having anything similar to navigate. Amran also continued to have occasional sessions with a parent worker (not a child psychotherapist) at the clinic. These differences in treatment were the result of individual therapeutic need in the families.

Such differences are inherent in the child psychotherapy model. The scarcity of families within the clinic who fitted the criteria and were willing to engage with the research meant it was not possible to interview a sample who had had a more homogenous experience of the treatment. I wondered about ways of incorporating parents' views on these differences into the research. Had I attempted second interviews with the participants, as is sometimes practised within IPA, it might have been illuminating to have asked the parents for their reflections.

It was important to keep in mind throughout that this research, with its in-depth focus on three participants, could not be generalised beyond their particular experience.

Theme validity and reliability

Bearing in mind the parents' communications about the significance of the parent work, both for themselves and in understanding their child, on reflection, it may have been illuminating to have retained the brief interviews with the parent workers that were part of the original study design (see 3.2.4) This element of the research was discarded (see 3.3.4) in a bid to narrow and deepen the focus of the study and avoid any unhelpful and distracting comparison of perspectives which is arguably not compatible with IPA. However, using clinician interviews for context in the discussion, outside the methodology may have been possible.

I outline my decision against using the data from the expanded therapist interviews in the discussion chapter later in this evaluation (see 7.5) when considering implications for future research. A different possibility might have been to carry out the brief interviews with the parent workers, as the clinicians closest to the parents' experience, and to draw on this material in the discussion. The thoughts gathered may have provided valuable additional context for the research findings, such as *loss of the typical child in context* (reflections on changes and endings in the therapeutic provision) and *desire for help* (relationship with the parent work). Standing outside of the methodology, this additional context may have provided further triangulation for the themes and strengthened the research by adding to theme validity and reliability.

7.4 Reflections on the methodology

In this section I will consider further the strengths and limitations of the study though reflections on the IPA methodology. I will discuss the value of the child psychotherapy training to IPA and vice versa.

7.4.1 The value of child psychotherapy to IPA

The child psychotherapy researcher

As Smith *et al.* (2009) stated, in IPA, "The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (p53). Researchers from different disciplines will bring particular qualities and skills, as well as limitations, to their use of the IPA method as a consequence of their training. Along with Watt (2019), I consider that the child psychotherapists' conceptual framework and clinical skill "can bring valuable understanding as well as new tools to the process of research" (p197). As different disciplines, and the clinicians within them, use IPA, so it evolves. I will now reflect on some of the skills the child psychotherapy researcher can bring to the method drawing on evidence from the findings.

Observation skills

As McGregor Hepburn (2018) stated, “Describing is not enough for this method” (p60). The child psychotherapy training involves a pre-clinical masters’ degree that aims to finely tune observational skills. Through post-session reflective write-ups of baby and young child observations, as well as work discussion, the trainee learns to notice and hold in mind information about themselves and their subjects in minute detail. Such skills, which are core to child psychotherapy clinical work, were invaluable during the research interview and analytic process, through observations of the participant, researcher and the interaction between them.

Hollway and Jefferson stressed the importance of recognising that, during the research interview, “the story told is constructed … rather than being a neutral account of a pre-existing reality” (2013, p29). Observing in detail produced rich data from within the context of the research relationship at a particular moment in time, which arguably added depth to the inquiry.

Triangulation

In-depth observation allows for additional triangulation during the research process as different sources of evidence build validity for themes. In this study, knowledge was accumulated through observations of tone, inflections, pauses, coughs, physical movements and emotional communications. This unconscious material is not usually visible in the transcript of the participant’s words alone. For example, when Christine spoke about psychotherapy as “amazing”, her words in the transcript appeared to communicate an idea of something magical or religious. The analysis of this passage revealed greater complexity. There was a hollow quality in the way the words were delivered which to my mind communicated something of the ambivalent feelings towards help in this moment.

Following the analysis, further triangulation was provided by examining the reflective journal entries, particularly observations from the first contact with the participant as well as reflections from before and after the interviews. This information was of limited use on its own and was bracketed off, but added validation to themes such as *life-giving help* and *gratitude* after the data analysis.

As Rustin and Rustin noted, “neither grounded theory nor IPA, in the work of its mainstream practitioners, has previously given much attention to unconscious mental phenomena" (2019, p19). For the psychoanalytic researcher, observing beyond words is essential, facilitating greater contact with and a deeper understanding of the participant's experience.

Whilst non-verbal evidence is particularly valuable to the IPA process, it is important to keep in mind that it can be a challenge to communicate to others in succinct presentations or summaries. It can be hard to find brief quotes from the transcript to satisfactorily illustrate themes, as can be seen in the *overcoming* theme in family 1 which was evidenced particularly through delivery.

Observing the self as researcher

The child psychotherapist researcher has had a substantial personal analysis, crucial in enabling the therapist to be able to differentiate the self from the patient. Analysis fosters a capacity to reflect on the self, which is a helpful tool for the researcher when identifying preconceptions. When Amran spoke in the interview about the value she placed on the practical help she received from clinicians in managing her daughter, I observed disappointment in myself, "my heart sank". I noticed my ambition for my research and the profession and after reflecting, could bracket off my bias. I later came to understand the huge value of this practical kind of help as part of the intervention, particularly at the beginning of work with families. Klauber (1999) highlighted the need for making conscious such feelings in clinical work with these families, so that preconceptions, clinical ambitions, fears and fantasies "do not excessively impede our way towards understanding and containing highly traumatised parents" (p34).

Generating rich data

Through presenting in the IPA regional forum and in supervision, I became aware that this research had generated particularly rich data. I have already described the role observation skills played in facilitating this.

As Hollway and Jefferson (2013) explained, the question-and-answer style of interview tends to inhibit. Facilitating participants to tell their story "stays closer to the actual life events" (p30). The participants in this research were extremely generous and shared their experience in depth. As discussed in chapter 4, research ethics, their previous experience of the parent sessions meant these parents were more familiar with the style of the interview than participants in some other research studies would be, perhaps allowing them to be more comfortable sharing their thoughts and feelings. *Gratitude* for the work also seemed to play a significant role in motivating the participants to tell their stories in an honest and open way.

I considered an additional factor. In my reflective journal, post-interviews, I observed myself in the researcher role. I noticed in my efforts not to lead the participant I frequently used non-verbal communications to communicate my engagement with their story, and that seemed to be helpful. I saw a parallel between the researcher role and that of the observer in infant observation; a central part of the pre-clinical child psychotherapy training. In both situations, it is helpful to develop a rapport with and response to the participant, without interpretation or by relying on language. Here is an extract from analysis A with family 1 (figure 31).

Figure 31: Extract from analysis A – family 1 (relating to quote 12)

> At the point she laughed I remember trying to show understanding of this feeling in my face. I also made some kind of acknowledging vocalisation. I felt she was expressing something quite strongly about how hard this was and I wanted to meet this feeling.

The child psychotherapy training with its substantial infant observation experience arguably produces researchers practiced in allowing space, tolerating anxiety and responding non-verbally so that a story can be told. Hollway and Jefferson (2013) referred to the value of these skills “in eliciting the kind of information that we require for our kind of research” (p81).

Researching distressing material

The exploration of loss in this research required an engagement with extreme experiences. In Amran’s interview, I became concerned for her state of mind as she communicated and re-lived the impact of loss and the resulting depression. The following extract was taken from a period when Amran had been speaking about her distress for quite some time, powerfully communicating the deathly quality of her experience. She appeared to become lost in the detail of her depression, going round in circles with no way out of her feelings. I began to feel that she might need some help. I kept in mind the clinical parent session which was due to follow our interview and the boundaries around our research meeting. In the moment, I used a brief comment to make a link to what she had already told me had been so very helpful for her (see figure 32).

Figure 32: Extract from transcript – family 3 (line 363)

> Amran - I was in, I had very severe depression (R - hmmm). That's depression. And the small tasks like cleaning or cooking seemed very difficult for me. And afterwards I was feeling very exhausted, very tired. I just did these small things for Jemima. If Jemima were not there, I wouldn't have done that, believe me, like cooking or looking after her (Sigh)
> R - (Pause). And then you started ... ?
> Amran - yeah, then I started. I talked to my GP and I talked to one person here, I can't remember. Then I was referred to psychotherapist.

Amran slowly took hold of my suggestion. She remembered the psychotherapist she met with, the talking, the tears and her painful, slow recovery. She was able to move on. At another moment, when I mentioned the parent session following our meeting which she had temporarily lost sight of, Amran replied with "yeah, you remind me," with relief and gratitude in her voice.

Being able to draw on clinical skill when needed in the research context allows for a deep exploration of painful emotional experience in a safe and ethical way.

7.4.2 The value of IPA to psychotherapy

I will now consider the ways IPA research can be valuable to the child psychotherapy clinician.

Honing clinical skill

The analytic process involved in an IPA study is extremely detailed, involving months of reflective work on a small number of participants' data. Analysis A involved listening to and reading the participants' interviews four times. This meant I was repeatedly able to pay close attention to my thoughts, associations and feelings. Audio recordings are not typically used in child psychotherapy clinical work (although Creaser's (2019) study findings suggest they could facilitate greater depth of understanding when used alongside clinical process notes). In this research, audio recordings offered an opportunity to "experience again", making contact with how moments felt in the room. The luxury of this degree of attention, the "slowing-down of coming to conclusions inherent in the further level of scrutiny” (Rustin and Rustin, 2019 p21), is not usually possible for the clinician. I noticed how the process seemed to hone my capacity to observe myself and I reaped the benefits in my clinical work.

Insight and evidence

The analytic process at times allowed links to form in my mind that surprised me. Connections between themes began to appear, such as *fear of causing damage* and *anger with connecting* in family 2. This link became visible to me during the writing up process. As Smith *et al.* explained, writing up is an important part of the analysis, “as one redrafts the analysis will become clearer” (2009, p182).

IPA provides a way of to triangulate instinctive feelings about patients. The method respects the complexity of psychoanalytic cases (Urwin, 2007a) and through it, evidence evolves that crucially is visible and examinable for others inside and outside the profession.

A different space to reflect

The IPA researcher in this study is outside the clinical work but alongside the participant. The researcher has technical skills but is not being clinical. There may be something about this unique position that allows even more insight into the process of reflecting on the work that was not so possible from within it. For one of the cases, the parent worker for the family was the supervisor for this research project. She noticed that the interview facilitated a different degree of reflection and honesty than had been possible in the parent sessions themselves. There could be an argument here for researching other people’s work rather than one’s own.

Summary - evaluating the research

In this section, I have outlined the limitations of this research and considered the strengths child psychotherapy training offers to the application of the methodology, as well as the value of researching using IPA for the clinician.

Through this discussion, I aimed to add to the evidence for how this study fulfils Yardley’s (2000) criteria for validity in qualitative studies. Smith *et al.* (2009) proposed that the criteria are relevant in IPA research in the following ways (p181):

1. *Sensitivity to context*

    - Producing a good interview by showing empathy and putting the participant at ease
    - Using a close attention to detail during the analytic process
    - Final report makes use of a good degree of verbatim from the participant’s material to allow the reader to check the interpretation as well as an awareness of the existing literature
2. *Commitment and rigour*
    - An appropriate, homogenous sample
    - Close attention paid to the participant during the interview and care taken with analysis
    - Communicating something important about the individual participant alongside the shared themes
3. *Transparency and coherence*
    - Clear description of the stages of the research process and analytic steps
    - Themes presenting a coherent argument
4. *Impact and importance*
    - Telling the reader something interesting, important or useful

7.5 Implications for future research

This study sits within the context of a defined topic of research - work with parents within child and adolescent psychotherapy. Further research is needed to examine this field in more depth. I will now outline some possibilities for future research that have arisen from this study focussing on parents of children with autism.

7.5.1 Clinician interviews

During the analytic process, a decision was taken to bracket off the interviews I had already conducted with the therapists in each of the three cases in order to focus in-depth on the parents’ views. Whilst writing the discussion chapter, I gave thought to the possibility of using the therapist interviews to provide context for the findings, informing from outside the methodology and perhaps providing an additional element of triangulation.

I considered two different methods to achieve this. Firstly, selecting a sample of each therapist interview to see if the themes were present. Secondly, applying a Template Analysis, where a template is created from the main study to consider how well it fits the second sample.

However, when I returned to the therapist interviews and their initial analysis after an interval of two years, I became aware of how much rich data I had gathered and considered that neither of the two options felt appropriate. I was keen for the therapist interviews to be analysed to the same depth as the parent interviews, in order to produce committed, rigorous research.

With the appropriate permissions, the therapist interviews could provide useful and illuminating data for a related IPA research question. A comparison with this study may then be possible, considering different perspectives on a phenomenon: how they coincide and collide.

7.5.2 Other ideas

1. Fathers

This research suggests that it continues to be difficult to engage fathers, or secondary carers, both in child psychotherapy work and in research. I am curious about the views of the parent who has not attended the parent sessions, when the primary carer and child have been involved in the work. It would be interesting to understand more about this perspective on the intervention and its impact on the family perhaps through a small, in-depth qualitative study enquiring into the experience.

2. Working with parents or children together or separately

The findings suggest that a model of child psychotherapy which includes both parent and child is particularly valuable when working with families of children with autism. Such a model may involve parents and child in the room together, or work with separate clinicians, but with a focus on frequent feedback to the parents about the work with the child.

However, there are situations where this kind of model is not manageable for a family. The findings of this study point to benefits for the child even when the parent is not engaged in their own parent work. I have heard opinions amongst clinicians that the focus in this field should be work with parents and less on therapy for the child, particularly considering the limited resources available.

It could be helpful to understand more about the value of child psychotherapy when the intervention is experienced by only one of the parent/child dyad. This might be achieved through a qualitative retrospective study, interviewing a small number of families who have accessed the intervention in this way, perhaps with some comparison with families where parents and child have all been actively involved in the work. Such a study, like the study suggested above, would add to the evidence base on parents' views of child psychotherapy.

3. Current views and practice in the profession

It would be helpful to have a clearer picture of work with children with autism across the profession, as well as an idea of common views on the intervention for this client group within multidisciplinary teams. A quantitative study looking at the number of cases child psychotherapists have or are currently working with in CAMHS teams and other multidisciplinary settings could be followed up with a qualitative investigation into views of work with this population amongst child psychotherapists and their multidisciplinary teams. A researcher or researchers could work closely with the relevant ACP Supported Clinical Network (once established).

7.5.3 Further IPA studies in child psychotherapy

I hope this study has shown that IPA is a valuable method for child psychotherapy research. It would be helpful to have a greater number of research studies by child psychotherapists using IPA as a methodology. This would add to the evidence base for the profession, enhancing "the transparency and accountability of psychoanalytic findings" (Rustin and Rustin, 2019 p21), as well as providing a meaningful contribution to the evolution of IPA as a research method.

Final thoughts

Through the IPA method, the researcher aims to try to understand the meaning of the experience for the other. There is a link to the clinician's struggle to understand **with** the patient. Both clinician and researcher accept with humility that one can never fully understand. However the attempt to try is of crucial importance.

I hope the findings of this study help shed light on the appropriate nature of child psychotherapy as part of a package of support for families of children with autism as well as what parents view as important development in themselves and their children.

This research developed out of my experience of working with families as a music therapist. The child psychotherapy training and placements helped me develop new insight and understanding of autism as a condition and the role of therapeutic support for families. I am very grateful for the generous contribution the parents made to this study and the support I received through supervision. This research has strengthened my commitment to the work and underpinned my intuitive feelings about its value.

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Appendix A Participant Information Sheet - parents

Study of child psychotherapy with children with autism: parents' views

We are pleased to have the opportunity to look in more detail at parents' views of their child's psychotherapy treatment. We invite you to take part in this research study.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You are free to decide whether or not to take part. If you choose not to, this will not affect the care you receive from [redacted]. If you do want to take part now, but change your mind later, you can pull out of the study at any time. Please ask if there is anything that is not clear.

Summary of research study

We are very interested in how parents of children with autism who have received intensive child psychotherapy feel about the treatment now. Did the therapy help your child and/or family? How did it help? What was difficult about the treatment? Did any improvements last?

We need more research into the effectiveness of child psychotherapy with children with autism. This research may help us to understand more about the ways intensive psychotherapy could help a child and their family.

Why am I being invited to participate?

We are inviting all parents to participate whose children (aged under 10 at the start of treatment) have received at least a year of intensive child psychotherapy. Your child may have a diagnosis of autism or autistic features identified in a related diagnosis. The intensive therapy will have ended between 6 months and 7 years ago. If possible, we are hoping to speak to five sets of parents with a range of views about the intensive therapy.

What's involved?

After reading this information, if you are interested in being part of this study, you will have the opportunity to discuss the research further, meet Rachel Bull, the researcher, and ask any questions you may have. This discussion could take place at MOSAIC or by telephone if you prefer.

If you decide to take part, we will ask you to attend a meeting with Rachel to reflect on your child's therapy. This will take place at [redacted], or if this is not possible, could be arranged in your home. The meeting will last for one hour and could involve one or two parents. If we haven't covered all the topics needed in one hour, we will ask you to attend one more meeting for a further hour. The meeting will be audio recorded and transcribed by the researcher.

We are also interested in the opinions of the child's therapist and the parent worker. Rachel will gather the views of these clinicians through a brief interview with them and also by looking at the therapist's' letters, summaries and the clinic's routine outcome measures.

You will receive a summary of the research findings at the end of the study.

What are the possible benefits of taking part?

You may welcome the chance to reflect on and express an in-depth opinion on your child's intensive therapy. Your anonymous opinions could influence the way this treatment is offered at [redacted]. Your thoughts may help another family make a decision, and may add to the understanding of child psychotherapy and children with autism in other teams.

Further supporting information

- All the information collected in this study will be kept confidential in accordance with the Caldicott principles. Audio recordings will be encrypted. Names and identifying information will be kept securely away from anonymised transcriptions. Recorded discussions will be erased at the end of the study. Pseudonyms will be used and identifying features disguised in writing up the research.
- Travel expenses for meetings at [redacted] would not be provided.
- If you have any questions or complaints during the study about the research, please contact [redacted] (or [redacted]) on ....
- The researcher, Rachel Bull, is a doctoral student employed by the NHS. The research is registered with the University of East London.

What happens next?

A member of the team who you don't already know will telephone you in two weeks' time to check that you have received this information and answer any questions. If you are interested in taking part in the study, we will arrange for you to meet Rachel in person or on the telephone to discuss the research further. You will then be asked to sign and return the consent form.

Appendix B Consent Form - parents

Participant Identification Number:

CONSENT FORM

Study of child psychotherapy with children with autism: parents' views

Name of Researcher: Rachel Bull

Please initial box

1. I confirm that I have read the information sheet dated................... (version #2) 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, without my medical care or legal rights being affected. ☐

3. I understand that my meeting with Rachel Bull from [redacted] will be audio recorded and transcribed by her. I give consent for this. ☐

4. I understand that relevant sections of my child's notes, relating to their psychotherapy treatment, may be looked at by Rachel Bull. I give permission for Rachel Bull to have access to these records. ☐

5. I agree to take part in the above study. ☐

______________________	______________________	_______________
Name of Participant	Date	Signature
______________________	______________________	_______________
Name of person taking consent (if applicable)	Date	Signature

Appendix C Parent Interview Questions for comment

Study of child psychotherapy with children with autism: parents' views

How do parents of children with autism who have received intensive child psychotherapy feel about the treatment now.

Parent interviews

Interview method - **Interpretative phenomenological analysis** (**IPA**) is an approach to psychological qualitative research which means that it aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon. Usually these phenomena relate to experiences of some personal significance, such as a major life event, or the development of an important relationship.

Questions

Things to have in mind

- Questions should be open and are simply to aid reflection
- Start in a general way and then prompt
- Questions should not take the participant in any direction
- Don't presume anything
- Not too many
- They don't have to be the same for each interview

Areas of inquiry

Parents' understanding of and feelings about

- intensive child psychotherapy – before, during and after the intervention
- the child's experience of the intervention
- any changes during and after the intervention
- parent sessions/their own involvement

Introducing the interview

Explain that I am interested in hearing anything they want to tell me about their experience. My questions are to help with that. They can tell me whatever comes to mind.

1. **Can you tell me about your experiences of intensive child psychotherapy?**

Prompt

- Can you tell me about the beginning?
- Could you tell me a bit more about that?
- Do you remember why you went?
- It ended (give date) Do you remember what was going on for you then?

2. **What did you feel about child psychotherapy before the work began?**

Prompt

- What did you have in mind when you started child psychotherapy?

3. **Whilst the therapy was happening, where there any changes?**

Prompt

- At school?
- Home?
- Any other aspects?

4. **What was your experience of the therapists' feedback**

Prompt

- What did you think of their reflections?
- How did you find the review sessions?

5. **What happened after the therapy?**

Prompt

- For your child?
- For you?
- Do you remember how long you felt that?

6. **Can you tell me about your experience of the parent sessions?**

Prompt

- Can you remember how you felt about beginning parent sessions?
- Can you remember what it was like to meet with .....?
- Can you remember ending?

7. **What are your thoughts about intensive child psychotherapy now?**

Prompt

- Has there been any change in your opinion?
- In relation to other interventions?

Appendix D Participant Information Sheet - clinicians

Study of child psychotherapy with children with autism: parents' views

We are pleased to have the opportunity to look in more detail at parents' views of their child's psychotherapy treatment. We invite you to take part in this research study.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You are free to decide whether or not to take part. If you choose not to, this will not affect your relationship with the clinic. If you do want to take part now, but change your mind later, you can pull out of the study at any time. Please ask if there is anything that is not clear.

Summary of research study

We are very interested in how parents of children with autism who have received intensive child psychotherapy feel about the treatment now. Did the therapy help the child and/or family or not? How did it help? What was difficult about the treatment? Did any improvements last?

We need more research into the effectiveness of child psychotherapy with children with autism. This research may help us to understand more about the aims of intensive psychotherapy with children with autism.

Why am I being invited to participate?

We are inviting all parents to participate whose children (aged under 10 at the start of treatment) have received at least a year of intensive child psychotherapy. The child may have a diagnosis of autism or autistic features identified in a related diagnosis. The intensive therapy will have ended between 6 months and 7 years ago. If possible, we are hoping to speak to five sets of parents with a range of views about the intensive therapy. We also want to gather the views of the clinicians in each of these cases.

What's involved?

We are interested in the opinions of the child's therapist and the parent worker in each case. The researcher, Rachel Bull, will gather the views of the clinicians by studying your letters and the summaries of each term's work. Following this, you will be asked to participate in an interview (50 minutes) about the therapy. This will either take place during work time, in person or on the telephone.

You will receive a report of the research findings at the end of the study.

What are the possible benefits of taking part?

You may welcome the chance to reflect on your work. Your anonymous opinions could influence the way this treatment is offered at [redacted]. Your thoughts may help therapists discuss intensive therapy with parents, help a family make a decision about treatment, and may add to the understanding of child psychotherapy and children with autism in other teams.

Further supporting information

- All the information collected in this study will be kept confidential in accordance with the Caldicott principles. Audio recordings will be encrypted. Names and identifying information will be kept securely away from anonymised transcriptions. Recorded discussions will be erased at the end of the study. Pseudonyms will be used and identifying features disguised in writing up the research.
- Travel expenses for meetings at [redacted] would not be provided.
- If you have any questions or complaints during the study about the research, please contact [redacted] (or [redacted]) on ....
- The researcher, Rachel Bull, is a doctoral student employed by the NHS. The research is registered with the University of East London.

What happens next?

Rachel will contact you by email, in person or on the telephone to discuss the research further and answer any questions. If you wish to participate, you will then be asked to sign and return the consent form.

Appendix E Consent form - clinicians

Participant Identification Number:

CONSENT FORM

Study of child psychotherapy with children with autism:

parents’ views

Name of Researcher: Rachel Bull

Please initial box

1. I confirm that I have read the information sheet dated................... (version #2) 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 timewithout giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

____________________	______________	______________
Name of Participant	Date	Signature
____________________	______________	______________
Name of Research Team member	Date	Signature

Appendix F Clinician Interview Questions

Interview questions

Introducing the interview

Explain that I am interested in hearing anything they want to tell me about this child/family's experience. My questions are to help with that. They can tell me whatever comes to mind.

8. **Can you tell me about your experience of this case?**

Prompt

- Can you tell me about the beginning?
- Could you tell me a bit more about that?
- It ended (give date) Do you remember how you felt about the ending?

9. **Can you remember how you felt about the case before the work began?**

Prompt

- Clinician's previous experience
- Do you remember the reason for referral?

10. **Whilst the therapy was happening, where there any changes in the child/family?**

Prompt

- In sessions?
- Home/school?

11. **What was your experience of the parents' engagement with the work**

Prompt

- What did you make of their relationship with the therapy?
- How did they use the parent work
- How did you find the review sessions?

Appendix G Themes Table Analysis D – Table of Themes

Theme	family 1	family 1 quotes	family 2	family 2 quotes	family 3	family 3 quotes
1. EXPERIENCE AND IMPACT OF LOSS (autism and other life events)	Loss (8) *of ordinary child, pain of loss of intervention and house move (feeling painful loss)*	144 – "I always felt with O that he was behind this wall of very opaque glass"	Loss (15) of her own parents, missing out, loss of the ordinary child *(matter of fact)*	301 – "just get on and deal with the child you've got" 389 – "you know, blah de blah, severely delayed, d d d d, severely delayed. It made for horrible reading"	Deathly (51) Loss as extreme, enduring, depression, no hope *(devastation)*	229 – "she would stay like that for the rest of her life" 239 – "I just brought her here blindly"
	Hatred/anger (13) **Hatred** towards child/autism/intervention	263 – "hated having a little boy, brother"			Punishing critical voice (21) **Hatred** towards child/autism, diagnosis as punishment	132 – "she gave me a really hard time for that" 329 – "playing on this table innocently"
					Humiliating exposure (7)	185 – "maybe people look at me as somebody ..''
	Shock and disbelief (7) Shock and disbelief in level of impairment	22 – "we'd wake up in the morning and he'd chewed his bed"	Crazy Overwhelm (21) response to autism, desperation, something crazy	163 – "suddenly run across roads" 417 – "I was just going absolutely.."	Life changing shock (23) response to diagnosis, trauma, breakdown	324 – 5 "I had a nervous breakdown in this room" 313 – "my child, er my life completely changed"
	Ungrounded (4) Basics not in place	17 – "he was sleeping very badly (cough, cough)" 199 – "as a family we were ostensibly dealing with it"	Vulnerability (20) lack of resources, feeling small and alone	177 – "for a little, little one it's completely, completely different" 244 – "what on earth am I meant to do now?"	Unsteady foundations (22) nothing solid, fragile, confusion	118 – "there was a problem with everything" 355 – "I felt I was very fragile"

2. RELATION-SHIP WITH FEELINGS AND THE SELF	Engagement with pain (9) Being in touch with or distance from pain	278 – “we didn’t actually see it happen” 523-6 – “I was really, really struggling, T and I had a really difficult time”	Distancing (53) Avoiding, forgetting, physically moving away	111 – “he has autism, which gets forgotten about” 260 – “I’m going blank (laugh)’	Avoiding loss (7)	404-5 – “it’s important if N has more and more sessions. I hope these sessions not finished with N”
			Diminishing (35) The interview, therapeutic relationship, her situation, the other	203 – “I imagine he’s got no recollection of it at all” 512 – “so I think he was probably like neutral”		
	Murky confusion (17) distancing from pain	97 – “happy for it to be a little bit (pause) murky” 481 – “some kind of other thing happening”	Self reliance (27) Coping, no room for other	33 – “fortunately I can eat very quickly” 254 – “I don’t feel that I needed that support”	Pull towards loss (11)	37 – “sadly she left” 57 – “she left after one year” 308-9 – “the sad thing that they left”
			Avoiding knowledge/desire (79) no opinion, avoiding emotion	62 – “the psychotherapists think it’s worth it, I was happy to do it on that basis” 69- “because the city is really great about people having babies, you then get fired so (laugh)”		
	Guilt (20) Reflecting on capacities, limitations, self criticism	148 – “quite a skilled person to to get through to him”	Guilt (7) Lack of capacity to be with and guilt about that	476 – “one to one time is great if you could always do that”	Guilt (3) For hate/being rejecting	232 – “but of course I understand her condition”
			Fear of being Damaging towards son/service	19 – “is it to see whether you are going to continue it?” 167 – “as long as people weren’t trying to give him electric shocks”		
			Personal capacity (12) limitations	196 – “trying to fit it into your life” 783 – “if I had it now it would probably be a very different experience”		

3. RELATION-SHIP WITH HELP AND CHANGE	Exposure (10) by intervention, need exposed	163 – “a huge stigma” 335 – “his play involved family members”	Critical judgement (28) Having to get it right, punishing other	342 – “no one ever gave me an answer” 360 – “sometimes I wonder why they picked me”		
	Feeling Excluded (16) Being on the outside	79-80 – “they seemed very pleased that he was erm (pause), that he was, erm, receptive to psychotherapy”	Excluded/ Rejected (34) Not included, ending of therapy	170 – “I wasn’t actually in the room” 238 – “I didn’t get invited”		
	Disbelief/Scepticism /ambivalence (32) Disbelief in any help. Response to progress and not knowing	39 – “I wouldn’t have thought it would be something that she would have gone for” 560-1 – “not as life-changing as we found it, and not as satisfy..satisfactory”	Demanding, disappointing other (39) Needs not recognised. Help a demand	112 – “people might need to step back and think” 257 – “I had enough on my plate as it was”		
	Overcoming/ commitment (12) Overcoming negative response to intervention	47 – “go for it, intensive” 114 – “erm I always put it down to the psychotherapy” 503 – “I was very involved in that psychotherapy	Anger with connecting (9) Anger at being put in touch with loss/difficulty	259 – “I had enough..I can’t remember” 593 - “I hadn’t realised I was having sessions” 753 – “you have autism. It’s a bit like telling your child they’ve got blue eyes. It’s flippin’ obvious”	Desire for help (9) Eager for connection	53 – “eager to go with her” 403 – “I’m still eager”

	Linked up Understanding (51) Gained understanding of her son through parent work	95 – “I completely trusted L” 334 – “bridges were important” 367-8 – “making sense...things started to become clearer” 400 – “massive revelation”	Hopeful wonderings (33) Positive feelings about change/intervention/understanding	96 – “the whole package if you like... has helped O to be where he is today” 120 – “I would consider it again” ‘I do sometimes wonder..’ 702 – “the structure and all that kind of helps things”	Understanding beyond words (36) Linking up, being able to see for myself	64 – “I could see how effective it was” 137 – “I could feel it, I could sense it” 95 – “it was like integrated work”
					Establishing foundations (27) Slow steady progress	135-6 – “things collected and put on basis” 143 – “N started to settle”
	Crucial importance of help/experience (10) desperate state, religious language	195 – “I think I was ready to give anything a go” 407 – “insight into his soul”			Life giving help (15) Crucial help, fundamental change	168 – “amazing things..I can’t imagine” 423 – “very very important part in N’s development”
	Relief/gratitude/Joy (26) for skill, understanding, delight in her child	55 – “he seemed very quickly to understand” 108 – “his language just improved so much” 455 – “he’s amazing”			Hopeful gratitude (31) joy, relief, gratitude, hope	83 – “it was wonderful for me”

Appendix H REC favourable opinion letter

East Midlands - Leicester Central Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

07 March 2017

Ms Rachel Bull
Child and Adolescent Psychotherapist in training
Tavistock and Portman NHS trust
35 Crown Road
London
N10 2HY

Dear Ms Bull

Study title:	**How do parents of children with autism who have received intensive child psychotherapy view the treatment now?**
REC reference:	**17/EM/0052**
Protocol number:	**NA**
IRAS project ID:	**205186**

Thank you for your letter of 28 February 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [Approvals]		16 October 2016
Contract/Study Agreement [Statement of activities - 205186]		16 October 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance statement UEL]		21 December 2016
IRAS Application Form [IRAS_Form_19012017]		19 January 2017
IRAS Application Form XML file [IRAS_Form_19012017]		19 January 2017
IRAS Checklist XML [Checklist_28022017]		28 February 2017
Other [Louise Allnutt CV - 205186]		16 October 2016
Other [Schedual of events - 205186]		16 October 2016
Other [Insurance statement UEL]		21 December 2016
Other [Consent form clinicians]	#1	22 January 2017
Other [UEL Working alone policy]		26 February 2017
Other [Cover Letter]	# 1	26 February 2017
Other [PIS clinicians]	# 2	17 February 2017
Participant consent form [Consent form parents]	# 2	17 February 2017
Participant information sheet (PIS) [PIS Parents]	# 2	17 February 2017
Research protocol or project proposal [Research Protocol]	#1	20 January 2017
Summary CV for Chief Investigator (CI) [Rachel Bull CV - 205186]		16 October 2016
Summary CV for student [Rachel Bull CV - 205186]		16 October 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/EM/0052	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp. S. O'Neil

Mr Ken Willis
Chair

Email: nrescommittee.eastmidlands-leicestercentral@nhs.net

Copy to: *Professor Michael Seed*

Ms Lynis Lewis, NOCLOR

Appendix I HRA approval letter

NHS
Health Research Authority

Ms Rachel Bull
Child and Adolescent Psychotherapist in training
Tavistock and Portman NHS trust
35 Crown Road
London
N10 2HY

Email: hra.approval@nhs.net

12 April 2017

Dear Ms Bull

Letter of HRA Approval

Study title:	**How do parents of children with autism who have received intensive child psychotherapy view the treatment now?**
IRAS project ID:	**205186**
Protocol number:	**NA**
REC reference:	**17/EM/0052**
Sponsor	**University of East London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **205186**. Please quote this on all correspondence.

Yours sincerely

Aliki Sifostratoudaki
Assessor

Email: hra.approval@nhs.net

Copy to: *Professor Michael Seed, UEL, Sponsor Contact*
Ms Lynis Lewis, NOCLOR, R&D Contact

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [Approvals]		16 October 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance statement UEL]		21 December 2016
IRAS Application Form [IRAS_Form_19012017]		19 January 2017
Other [HRA response letter]		
Other [hra-schedule-events-205186_Validated by HRA]	1	13 March 2017
Other [statement-activities-205186_validated by HRA]	1	13 March 2017
Other [Louise Allnutt CV - 205186]		16 October 2016
Other [Insurance statement UEL]		21 December 2016
Other [UEL Working alone policy]		26 February 2017
Participant consent form [Consent form clinicians - 205186 v2]	2	11 March 2017
Participant consent form [Consent form parents]	# 2	17 February 2017
Participant information sheet (PIS) [PIS clinicians v2 - 205186]	2	11 March 2017
Participant information sheet (PIS) [PIS parents v3 - 205186]	3	11 March 2017
Research protocol or project proposal [Research Protocol]	#1	20 January 2017
Summary CV for Chief Investigator (CI) [Rachel Bull CV - 205186]		16 October 2016
Summary CV for student [Rachel Bull CV - 205186]		16 October 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Professor Michael Seed

Email: m.p.seed@uel.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	A minor amendment was made after REC favourable opinion to align the documents with HRA Approval standards, for example, about the research team having access to the summaries' of each term's work and the clinic's routine outcome measures.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Sponsor contact has confirmed that the Statement of Activities and the Schedule of Events will form the agreement between the Sponsor and the research sites. The applicant confirmed that no Participant Information Centers would

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			be used for this study.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No external funding is being provided for this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion has been issued.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a single site study where the site is responsible for all activities as stated in the protocol. The applicant confirmed that all research activities will take place at [redacted]

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Principal Investigator (PI) is expected to be in place at participating NHS organisations.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

It is unlikely that letters of access or honorary research contracts will be applicable, except where staff employed by another Trust (or University) are involved (and then it is likely that arrangements are already in place). Where arrangements are not already in place, external staff undertaking any of the research activities listed in A18 of the IRAS form (except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Corporate Services

Health and Safety Unit

Working Alone Policy

This is a sub-policy of UEL's main Health and Safety Policy Statement

Introduction

The purpose of this policy is to give guidance on the arrangements which apply to students and staff who work alone for some or all of their time.

Generally our staff (including research workers) can work safely on their own in laboratories/workshops and offices. However, a risk assessment must be undertaken to identify additional measures are required or any circumstances where it would be unacceptable to work alone.

Specific Restrictions

There are no absolute legal restrictions on working alone. However, there are certain types of work activity and work location where lone working is positively discouraged. Some examples of this are:

- Work that involves certain substances that are hazardous to health under COSHH (Control of Substances Hazardous to Health Regulations) e.g. fumigation work;
- Some work involving young people; especially where their lack of experience or maturity may interfere with their ability to identify risks;
- Some work at height; in particular the erection of scaffolding;
- Some electrical work; particularly work on or near live conductors;
- Most work in confined spaces

Other examples of solitary working which a risk assessment is likely to indicate as unacceptable include:

- Experimental operations involving hazardous chemicals or hazardous micro-organisms; Rotating machinery;
- Work with high energy or thermally unstable materials.
- Operations involving moving equipment or machinery, especially if not guarded;
- Transfer of flammable or corrosive chemicals.

This list is not exhaustive. Schools and Services will need to add other local activities identified by their risk assessments.

Permitted Solitary Work

Examples include:
Security function - night work
Desk work

Assembly of apparatus/workshop equipment or minor modifications which do not involve chemical, electrical and mechanical hazards.

First Aid

If a lone worker has a minor injury he or she may be able to use a first aid box or phone for assistance. A more serious injury may result in the injured person being incapable of self help. Where serious injuries are foreseeable then the absence of a colleague to administer first aid or at least call for help can be regarded as insufficient first aid cover.

Safe System of Work for Solitary Work

Where a decision needs to be made on staff/students working alone the following points must be considered:

- the need for a detailed risk assessment;
- the remoteness or isolation of the workplace;
- the nature of anticipated injury or damage ('worst case' scenario);
- communication difficulties, and threats and opportunities e.g. criminal activities, interference etc.;
- information, instruction, training and supervision to enable individuals to recognize and appreciate the hazards and risks involved in working alone.

Rules and procedures should be developed to ensure appropriate:-

- Authorization by the Dean of School/Director of Service/supervisor following completion of risk assessment;
- Required ability/competence of employees e.g. medical fitness, professional training; Suitability of equipment e.g. quality, quantity and personal protective equipment; Communication - how, frequency, alarm system, phone etc.;
- First aid arrangements - e.g. travel kit;
- Emergency procedures e.g. getting help, rescue plans;
- Specialist training e.g. for equipment.

The above procedure and information may be supplied in a permit to work format.

The most important rules are that:-

- The lone worker has full knowledge of the hazards and risks relating to his or her work activity;
- The lone worker is fully aware of the emergency procedures, including how to summon help.
- Someone else knows the location of the lone worker and suitable monitoring arrangements are being implemented.

Please refer to our Policy on Personal Security for further guidance.

Reviewed January 2016; Next review date January 2018.