# Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians?

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1. Parental Trauma – Parents' theme 1 and focus group theme 2
2. Living with uncertainty – Parents' theme 2
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All names and identifying details have been changed where possible to protect anonymity

# Dedication

I have many people to thank, including Anne Zachary, Lucia Genesoni, Elena Della Rosa, Alison Cantle, Jennifer, James and Benjamin Hamilton. However, this work would not have been possible if it had not been for the enduring support, love and patience of my husband, Rob. This work is dedicated to him.

## Abstract

This study aims to examine the lived experiences of four parents accompanying their child in a complex neurodevelopmental assessment. It attempts to understand what the parents experienced in the assessment particularly in relation to the clinicians and why, and how this might contribute to the outcome of the assessment. Free Association Narrative Interview (FANI) method and Interpretative Phenomenological Analysis (IPA) was used. FANI is designed to work with defended subjects, and IPA aids the researcher to identify themes that may not be apparent at first. As well as interviewing parents, the staff group of assessing clinicians were interviewed within a focus group. This aimed at understanding their counter-transferential responses to the parents in the assessment situation. This had the goal of understanding the parents' unconscious communications and motivations within assessment to further inform on the parent's experience. It is hoped that this additional data will inform on the outcome and feedback aspects of the assessment by enlightening why clinicians might make decisions or process the assessment in particular ways.

The following themes are described, with the first three belonging to the parents and a further three belonging to the clinicians:

1. Parental trauma and the role in the child's difficulties
2. Difficulty, uncertainty and the development of epistemic trust
3. A persecuted state of mind: how assessment effects parental sense of self and clinician

1. The clinicians' experience of knowledge and power

2. The presence and management of parental trauma in the assessment framework
3. The need for time in processing conflict and coming to a conclusion

These themes are examined in relation to current research as well as psychoanalytic literature of internal processes. There are conclusive remarks around the presence of defensive states in parents as well as in clinicians which hinder the understanding of the child’s difficulties and there is discussion around why this may be. Recommendations for coping with the increasing demand for neurodevelopmental assessment are made by way of linking what parents want to what it appears they might need.

# Introduction

## Complex neurodevelopmental assessment in Child and Adolescent Mental Health Services (CAMHS) - Assessing the situation

Autism Spectrum Condition/Disorder (ASC/D) and Attention Deficit (Hyperactivity) Disorder (ADHD/ADD) as well as other neurodevelopmental and executive functioning disorder diagnoses, are increasing globally (CDC, 2018, Elsabbagh, 2012 & NSCH, 2011). One reason for this might be that clinicians have more sophisticated understanding of these conditions and, therefore, are better at detecting them, but they also have more ideas about how best to intervene to lessen the negative impact on the child and family. The prevalence of media support for neurodiversity is self-evident. It might be said that, today, having autism or ADHD is more socially acceptable, understood and even celebrated at times. They are not always considered the terrible life-sentence they once were. Another side of the clinicians' increasingly sophisticated understanding of conditions, such as autism, is that they can see the spectrum of traits in finer detail, meaning that a diagnosis of autism has a much wider, varied meaning than it did before. A diagnosis of autism, for instance, still requires a deficit of proficient functioning in the classic triad of areas as described by Wing (1988) – restricted interests, social interaction, and verbal and non-verbal communication, but the clinicians' sensitivity to these deficits has increased.

Broader, more integrated perspectives of atypical neurodevelopment are becoming mainstream. More is known about how the brain changes in reaction to emotional experience and how emotional experiences are more or less likely depending on particular neurological pathways. So, clinicians are starting to look more at the relationship between these variables rather than the more polarised views that have previously dominated debates. Clinicians are thinking less about whether atypical neurodevelopment is either genetic endowment or due to a massive deficit in the environment – our old friend: nature or nurture – but much about more how they interact (Singletary, 2015)

With this increase in understanding and identification of traits, has come an increase for formal assessment. These can be more complex assessments and involve more complex routes to even get to the assessment stage. A multi-disciplinary assessment from a CAMHS team will often be conducted prior to a more confirmational diagnostic assessment such as the Autistic Diagnostic Observation Schedule (ADOS). This will include taking detailed developmental histories, school observations, and reports from schools. It's a thorough and resource heavy process that aims to assess the situation and determine the ongoing direction of further assessment, therapeutic intervention, or signposting and discharge. These possibilities are wide ranging and can be dependent on the resources of the team or the area. There are often waiting lists, or other delays.

Within this context, a child psychotherapist's deeper understanding of the effects of relational experience and nuance can be beneficial but it can also open up more uncertainty and complexity.

As child psychotherapists, we understand the detail of the 'nurture' relationship and how the child's experience of the parent and the parent's experience of the child develops and affects the growth of the mind. Thankfully, we have moved on from the views of Leo Kanner (1949) and Bruno Bettleheim (1967) who initially took much more of a blaming stance towards parents. However, we know that parents can have their own struggles, or have difficult circumstances at the time of their child's inception, so these are important to consider in our understanding and supportive intervention whether that is in the form of a diagnosis or not. However, despite our academic understanding ruling out parental blame, anecdotally the investigation of the external circumstances of a case can certainly be *experienced* as blame by parents. Practitioners may even experience urges to attribute the child's difficulties to the parents, parents may feel as if it is their fault that their child is struggling, so again this is an important area to research and increase our thinking on.

It was in my two training posts that this drive to think more about parental experience arose. Initially, it arose while working in an autism team, working with families who were struggling with the meaning of diagnosis, wondering which behaviours to address and how, whether to attribute them to autism for instance or something else. In particular, I worked intensively with a boy with event trauma in his past and a diagnosis of autism. All of his difficulties were attributed to his autism, and his development was inhibited partly because of this. I began to wonder what a lifelong diagnosis might mean to a parent compared to one that was more temporary and more treatable. In this same case, I wondered why the diagnosing clinician had not thought to offer treatment for loss, grief, anxiety and relational difficulties all of which were quite clearly present in the family. I wondered why the focus had become autism rather than a disturbance in the primary relationships. I wondered what might have been missed or avoided? What happened between the assessing clinicians and this family so that they came to this particular pathway?

Furthermore, my need to further reflect on the parental experience continued in my second post in a clinic that holds the neurodevelopmental assessment referral pathway for a large part of the local area. I began observing what the clinic calls 'complex neurodevelopmental assessments'. The referrals for this assessment clinic came from a wide area and were, as the name suggests, complicated. Often questions around autism or ADHD were posed. Sometimes neurodevelopmental diagnoses were made, but often there would be discussion about the relational aspects of the case and ponderances over whether an outcome of ‘attachment disorder’ or similar would be more appropriate. Difficulties arose when there were tensions between clinicians and parents about what each diagnosis would mean for the child in terms of access to treatment, support or extra academic help. The clinicians in the clinic often felt pushed for time, both to discuss these issues but also to feedback to the parents. My psychotherapy colleagues helped me think about the short comings of this brief feedback session and what it might mean for the families but also for the ongoing provision of help for what usually remained a complex case.

In this study, I aim to explore the parents’ experiences of this assessment. I hope to achieve some further understanding of parents’ experience of the first signs that their child might need neurodevelopmental evaluation, the pre-appointment drive for information, the experience of the assessment itself and also the feedback session and resulting advice. I hope that with a psychoanalytic stance, I might better understand the drive for assessment, and the experience of the outcome in a meaningful way. I have employed an interview method - the Free Association Narrative Interview method (FANI) - that emphasises the importance of allowing for the unconscious to show through which is an important aspect of psychoanalytic work, to deepen our understanding.  As well as interviewing parents themselves, I ran a focus group of the clinicians who run the assessment. The purpose of this was to gain an insight into the counter-transference experience that could inform further the understanding of the parents’ experience.

## Structure of this thesis:

Chapter 1 is dedicated to the literature review, which is comprises three main areas. Firstly, I describe some of the most prominent research that has been done over the last 15 years that investigates parental experience of neurodevelopmental assessment. These are not written by psychoanalytic child psychotherapists, rather more so by educational psychologists, clinical psychologists and dedicated researchers. Their outcomes inform clinic procedure, but do not necessarily deepen our understanding of the less conscious, relational aspects of a CAMHS assessment.

Secondly, I describe the psychoanalytic literature, which informs our understanding of primitive and unconscious communications of children and parents. I present literature that describes anxieties and defences, both in autistic children, those with ADHD and more ordinarily developing children. I will look at papers that discuss how parents experience psychoanalytic types of assessment, again for children that are both neurodevelopmentally diverse and those who are not. I discuss some of the dynamics of the parent-child relationship and how we understand them when a child is brought for assessment and/or treatment.

Lastly, I present briefly the literature on group processes that can affect staff and how this might link in with working with parents who attend this clinic with their child. This is to add a further dimension, through the use of counter-transference, to the understanding of parents at this time.

Chapter 2 describes the research aspect of this thesis: the method by which I designed the procedure, recruited parent participants, and analysed the resulting data. Chapter 3 presents the results that emerged from the analysis of the data.

Finally, in Chapter 4, I discuss my findings in relation to the literature that I have written about below. I hope that this will both inform clinic practice, but also draw together the research that psychologists have conducted into parental experience with psychoanalytic understanding of it.

# Chapter 1

# Literature Review

## 1.1 Introduction

This is a narrative literature review which aims to outline some of the present research papers, neuropsychological and psychoanalytic papers which addressed the research question: Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians?'.

In the following section, I describe the methodology used to identify the relevant research papers Subsequently, I report on the research papers that I found in the area of neurodevelopmental assessment from the point of view of parents. In the second part of this literature review I discuss how the psychoanalytic and neuropsychological literature informs my understanding of aspects relating to autism, ADHD and brain development. Moreover, I discuss their interrelationships with an understanding of the parents' experience, as well as of the clinicians' experience, during a neurodevelopmental assessment.

## 1.2 Methodology for research papers

I conducted a literature search using one of the large electronic databases – PsychInfo. Beginning with my research question of 'Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians?'. After trying a number of terms and reviewing the results of each single term searches as well as terms linked by the Boolean operators ‘and’ and ‘or’ I settled with “autism assessment” OR “adhd assessment” OR neurodevelopmental AND “parents experience”.

Please see Appendix A for screenshots of database search for relevant literature. After this initial search period, and scanning the results for relevant papers, my final search gave me a list of six papers. Of these six, five were available to me. They opened up both my search for further papers and my ideas to areas of literature still to be read. A snowball technique was employed to broaden my exposure to multicultural and multi-disciplinary research into similar areas.

## 1.3 Research studies into parents’ experience of their child’s neurodevelopmental assessment

Below is a table (Table 1) of key features of the five key research papers resulting from my database search. In this section I concentrate on these studies as I feel that this helps to set the scene and provide a multi-disciplinary backdrop in which my research study may sit alongside. As it can be seen from the table, the studies have been conducted by researchers with different professional backgrounds all using qualitative design. The studies are different in their theoretical stance but similar in the questions the authors pose and explore.

Table 1: Key features of the five key research papers on parents' experience of neurodevelopmental assessment

| **Lead author** | **Pub. date** | **Design** | **No. participants** | **Age rage** | **Country** | **Discipline of researchers** |
|---|---|---|---|---|---|---|
| Hodge | 2006 | Phenomenological interviews of parents in the 'Lifeworld' narrative structure. | 3 | 3-6yrs | England,UK | Ed. Psych |
| Braiden et al | 2010 | Semi structured interview | 11 | 5-11yrs | N. Ireland, UK | Educational Psychologist, paediatrician |
| Desai et al | 2012 | Semi structured interview | 12 | 5-23yrs | Goa, India | Psychiatrist |
| Carlsson et al | 2016 | Phenomenological, structured interviews of parents | 11 | 4-7yrs | Sweden | Speech and language pathologist |
| Twomy and Shelvin | 2017 | Qualitative, longitudinal case studies from interviews | 6 | 2.5-6yrs | Ireland | Academic, professor of education |

The first author I report on is Hodge (2006) who examined the experiences of parents as they *approach* the autism diagnostic services. The study centres itself with the question of whether a diagnosis is always helpful, especially at a young age. Hodge reports on the polarity of experiences: those parents who fight to get the diagnosis and those who feel it as an intrusion. Questions are posed around the benefits and dangers of pathologising children and the enablement or disablement of the family as a whole. The crux of the findings centre around what the author describes as a circular journey from being parents to getting advice from professionals, finding this enabling and moving on to feeling empowered or disabling and having to work through how to receive professional intervention that is helpful. It is clear that the parents in this study went through a very personal journey of sense making within the context of professional relationships and intra-family relationships illuminating the meaning of the diagnosis for them as individuals. It examined who the child is in the parents' minds in relation to the diagnosis, and how they felt about themselves. Hodge's study emphasises the importance of understanding the parent/child relationship in connection to a potential diagnosis.

Braiden, Bothwell and Duffy (2010) explored parents' *experience of a process of assessment and diagnosis* of autism. The focus on the process highlighted the complexity of the diagnostic process.  There was some reflection on post diagnostic services.  They write about the responsibility on the clinicians to get the diagnosis right, and discuss the conflict between having an early diagnosis which allows access to resources, verses the possibility of coming to premature conclusions.

The authors identified the theme which was named 'Initial Concerns' which gives voice to the parents' grappling with their feelings that something wasn't quite right with their child. There was a concern that they, as parents, may not be taken seriously or believed by professionals. Later, once professional advice had been taken, and assessment was under way, parents were found to have strong feelings of uncertainty, being overwhelmed, and not feeling prepared for certain aspects of the assessment. These seem to all be related to a lack of control over the situation. There is a question around trusting that the professionals have made the right decision. The authors suggest that having a better idea of what to expect from the assessment would be helpful for parents.

After the diagnosis, a strong feature resulting from this study was the description of parents' experience of the diagnostic and feedback portion of assessment. Being given both the result/diagnosis and information about the condition, advice and the next steps seemed overwhelming and made it difficult for parents to process the emotional effect as well as the need to process information on a more intellectual level. This left parents often feeling as if they had missed something or not taken the opportunity to ask questions. Parents gratefully received written information when it was specific to their child and written in a way that they could understand. Finally, this study highlighted 'a void' between the end of the assessment and the next steps offered towards support. This time of coming to terms with the results of the assessment and the consequences left parents feeling unsupported.

Desai et al's (2012) study looked at a longer time-frame covering the parents' experience in relation to the child's life up to the current time of assessment and diagnosis. They identified four phases of parental experience tracking through the child's life. The first phase documented the child's early years of relative normality and being as the parent expected and had previously experienced. The second moved into the first signs and feelings that something wasn't quite right. There seemed to be a gradual move from wondering about a temporary behaviour or something passingly idiosyncratic to a concern that there was something pathologically wrong. Family culture as well as societal culture seems to play a big part here, perhaps being part of a reassurance or attempt to explain away concerns of something more serious.  Concerns around self-blame or guilt are documented in this study, as well as the experience of simply not knowing what might be wrong.

The third phase documented the time when parents' concerns moved more towards the beginning of a confirmation that a problem persisted and was causing distress and difficulty to the child and/or the family. First encounters with professionals seemed to be at this phase and the search for solutions.  This seems to be a phase of recovering from the shock and learning to cope given the new information. Finally comes the fourth phase; this seems to be a time to come to conclusions around the malleability of the condition, its permanence and the possible limitations. The authors describe a search for alternative reasons for their child's difficulties and finding a place for their own expertise about their child alongside that of the medical professionals. The authors finally press the need for family support through the life phases of diagnosis.

Carlsson et al (2016) explored the experiences of parents of children who were diagnosed with ASD. The children in this study were younger compared to Braiden at al (2010) and Desai et al (2016). The time-frame was also smaller, indeed, Carlsson and colleagues focused on the time after the initial screening onwards. They interviewed parents before and during assessment, and after diagnosis. The researchers describe the essence of their findings being around 'negotiating knowledge'. The themes are around the intercourse of parent knowledge and clinician knowledge. It seems that the parents' experience of the process evoked anticipation of a new role they will have to take on as parents of a child with a diagnosis. This presented new questions and unknowns but also conversely the experience of some stability – the diagnosis hadn't changed the child. Similarly, to what was found by Braiden et al (2006), an important point that emerged was the need for time to digest and think about meaning before moving on to the next stage of help.

Twomy and Shevlin (2017) conducted a study investigating parents' experience of assessment, diagnosis and early intervention. They looked at a population of parents whose child had received a diagnosis of ASD. The authors report on the traumatic assessment and diagnosis experience of some of the parents. Particularly, they report on how parents felt that professionals have 'over simplistic views of parenting' when trying to understand their child. The authors cite Carlhed at al (2003) describing the relevance of identifying parents' 'real and desired needs' and the importance for the parents to feel that professionals can work with them as a team. This seems to suggest how essential it may for parents to experience that their feelings and needs are understood when it comes to considering the care of a child with atypical neurodevelopment, and how without this a 'legacy of mistrust' can develop. Indeed, one of the key findings of this study was that professionals' view was that the parents were the ones that needed help. Frustration and anxiety leading up to diagnosis were clear, as was a sense of relief when the diagnosis was made. However, the authors press the need for 'newer understandings of [parents'] experience.

## Summary

The salient points from these five papers include an experience of uncertainty in the parents around whether the right decision was being made, whether the clinicians were seeing a true representation of the child in the limited assessment period, and whether their knowledge of the child was valued. This seems to suggest that there can be a tension in the parent/clinician relationship which may affect the reported levels of satisfaction from the parents. Whether or not this tension exists in any individual case, all of these five papers highlight the relationship between the clinicians and the parents as being central to the experience of the assessment as well as in the follow-up stages of feedback and support. The post diagnostic or follow-up stages were highlighted in all the papers, although with emphasis on greater need at different points: detailed, child-specific reports, multiple feedback meetings, quicker follow ups and more longitudinal support. None of the papers went into much detail if any about the clinicians' part in this relationship and how they negotiate with the parents. Hodge suggested that adjustments to recommendations need to be made when the parents disagree. However, potential difficulties around this were not further elaborated on.

Further, a point made by two of the papers (Hodge, and Carlsson et al) was around how a diagnosis may affect who the child is in the mind of the parents. This suggests questions around how this might impact on how parents make sense of them and any further issues in the future and, in turn, how this affects the developmental trajectory of the child.

From reading these research papers, other papers were identified that have significance to this area of study.

A large survey of parents' views of the diagnostic process was undertaken by Howlin and Moore (1997) with a sample of 1294 parents**.** The parents in this study were members of autism societies and therefore the vast majority of their children were those who had received an autism diagnosis. The authors found that families given a clear diagnosis of autism, and when the diagnosis was given early, were more satisfied with the assessment process. However, the resulting diagnosis had little relationship to satisfaction with the help received post assessment. These results seem to suggest that there is something important about not living under the shadow of doubt, rather than the diagnosis being necessary for accessing services or psychological treatment.

The importance of clarity in diagnosis has been further validated by a study conducted by Chao et al (2018) noted how difficult it could be for parents while diagnosis remained uncertain. They found that parents experience uncertainty as stressful, and that some questioned whether it was their parenting or own problems that were causing the difficulties. Travell and Visser (2006) write about parental ambivalence after an ADHD diagnosis, and a wish for more information. It seems that the uncertainty described by Chao et al is not relieved after the diagnosis. They recognise the personal journey that children and their parent go through in diagnosis and recommend a need for biological, psychological, cultural and social factors to be taken into consideration during the assessment and treatment of ADHD.

In a different way, the need for clarity seems to play a role also in relation to explain to parents the role of each clinician involved in the assessment procedure as found by Giannoulis et al (2004) who studied parental expectations and satisfaction with a specialist neurodevelopmental service and as reported by Braiden et al study above.

A small research study using narrative analysis was conducted by Aldous (2017) with two parents focusing on their experiences of being referred for a diagnostic assessment. Important aspects of her findings include the meaning of the medical diagnosis to the parent. Despite their positions to medical terminology, both participants were reported to have felt the need to regain some efficacy and control around their child’s situation. In discussing her findings, Aldous cites Lawson et al’s (2013) paper looking at the distancing effect that children’s diagnostic labels can have on the ‘sphere of influence’ of the adults using them. This suggests that an adult would attribute problems to the diagnosis rather than to anything within their control as a means of dissipating anxiety.

Additionally, relating to anxiety, Aldous uses a psychoanalytical frame of interpretation of her results and talks about the splitting-off of emotional experience as a defence against overwhelming anxiety. This theoretical description stems from Klein's (1946) work. Here, she describes splitting and projecting out of intolerable parts of the self. Aldous relates this to parents who project into their children emotional experiences that they themselves cannot bear. This could be particularly relevant when thinking about why parents seek out help and/or diagnosis and the importance to attending carefully to the narratives of these parents during the assessment process.

Finally, Buzanko's (2018) comprehensive literature review of parents' lived experiences of the assessment process towards mental health and/or neurodevelopmental diagnosis states that so much of the literature focuses on parents' experience of receiving a neurodevelopmental diagnosis. She highlights parents' expertise on the child and the need for this to be utilised during assessment. She suggests that gaining parents' input promotes parent engagement in treatment. From this it could also be surmised that having valued their input, the need to refer on may also be less problematic, and parents would feel less overwhelmed by the process. Much of the research cited in Buzanko's paper refers to issues relating to uncertainty; not know what was going to happen, how long assessments would take, waiting for results, and a sense that clinicians were not being transparent with them (Hackett et al, 2009, Mulligan, 2012, Cunningham et al, 1984; Quine & Pahl, 1987). Buzanko writes of unexpected diagnosis but not of null diagnosis. This paper notes that assessment is often a difficult and unsatisfactory experience.

In conclusion, the above research documents the very personal experience that parents go through from the moment that they consider that there may be something wrong with their child, to approaching services and all through the assessment and diagnostic process. Several mark out the anxiety that parents sit with while waiting with uncertainty. There does not seem to be much examination of whether uncertainty is much relieved after the assessment process. There are several indications of the importance of engaging with clinicians during this anxiety provoking time, and when working out how to address the difficulties, make sense of them and move forward in life. The mention of a sense of clinician's lack of transparency is interesting and points to a question of why this might be. There are thoughts about why parents might or might not want a diagnosis and what it means for their relationships with their child and sense of self and agency within it. These papers do not talk explicitly about those who were not given a diagnosis or if an unexpected diagnosis was given and how parents experienced the assessment process in this case. This is a significant void in the research.

## 1.4 The complex interplay between attachment, trauma and neurodevelopmental conditions

This section reports on relevant literature that explores the complex aetiology of neurodevelopmental conditions particularly with the understanding that attachment relationships are fundamental to a child's developmental and therefore need to be understood when development is atypical. The developing brain is affected by attachment relationships and by trauma (Shore, 2001), but relationships and experiences may also be affected by an existing neurological deficit (Singletary, 2015). It is with this complex interplay in mind that the following authors reported below seek to describe and apply their understanding for the benefit of clinical intervention.

For the purpose of this paper, trauma can be defined as ‘any disturbing experience that results in significant fear, helplessness, dissociation, confusion, or other disruptive feelings intense enough to have a long-lasting negative effect on a person's attitudes, behaviour, and other aspects of functioning.’ (APA, 2015). It is recognised that some events will be experienced as traumatic by some people and for others, not. This may be to do with how the event reawakens past, unresolved issues.

Early trauma can affect the brain at critical and sensitive times of development. These effects can then sensitise the neural pathways to further and even less severe moments of stress of trauma (Perry at al., 1995). Perry et al (1995) state *‘the single most significant distinguishing feature of all nervous tissue – of neurones – is that they are designed to change in response to external signals’* (p. 274). They go onto to reiterate that the brain’s structure is altered by all sensory signals. While an adult’s developed brain can be affected by trauma, a child’s brain is still in the process of organising and so these temporary states can quickly lay the foundations for more permanent neurodevelopmental traits. They also recognised that adults who were traumatised as well as or alongside the child can become vehicles of ‘vicarious traumatisation’ when they are not able to contain their anxiety.

When thinking about neurodevelopmental conditions, there is often a focus on brains. The term ‘neurodiversity’ is common in discussions around autism and ADHD. However, Rutter (2002) points out that environmental influences as well as genetic influences are important. Pozzi wrote a paper (2000) which unpicks the history of diagnosis and treatment of ADHD. She writes about the function of inattention and hyperactive symptomology. She describes situations when the child does not receive enough close and consistent attention or ‘containment’ (Bion, 1962) from their primary caregiver, causing them to turn to ‘second-skin’ (Bick 1968) like defences which often include a sort of muscular tension or overactivity, to avoid sensations of dread and collapse. There is statistical evidence of a higher incidence of ADHD in the looked-after-children population (Willis, Dhakras and Cortese, 2017) and in traumatised children and adolescents (Szymanski et al, 2011). Taylor (1994) and Clarke, Stiefel et al (2002) suggest that ADHD and attachment insecurity are associated. However, it is unclear whether insecure attachment is a cause or an effect of ADHD. Dinkler et al (2017) find evidence to suggest that when controlling for familial factors (i.e. genetic and shared environmental factors), childhood maltreatment (prevalent in the looked-after-children population) is not statistically positively correlated with ADHD. There remain many questions around the association between attachment and ADHD presentation, and the above literature show the complexity of their potential interrelationship. Pozzi’s paper concludes that there may have been a ‘failure in the containing function of the primary figure’ linking this to a possible cause of ADHD.

It seems important to mark that the primary figure and how their containing function is experienced by the child is affected by many factors. A parent may be doing as well as they can under difficult internal and/or external situations. The child themselves may have personality or neurobiological traits that make it more difficult for them to feel the attempts at ordinary containment. Maté (1999), a physician with a specialism in the biopsychosocial underpinnings of common health behaviour difficulties, gives an interesting and explanatory analysis of his own background which he believes is linked to his own diagnosis of ADD. His mother’s (quite understandable) preoccupation with the Jewish persecution in the 1940’s meant that she was far less psychologically available to him in his early years. Although this was clearly an extremely dangerous time in which to be bringing up a family, Maté reminds us that it is not necessary for a family to be under this sort of situation to '*trigger deep conscious and unconscious anxieties in the parents*.'(p93). Parents can be distracted and preoccupied even under the best material and social circumstances and '*even when the parents love their children and have nothing but the best intentions*.' (p93). Maté illustrates vividly how important it is to have a good understanding of the parents' situation and resources both at the time of inception, and at the time of seeking help, in order to understand how they may have been able to relate to their child and their child to them.

These pieces of literature indicate that the environmental experience, which includes early relationships, is crucial regarding the expression of genetic heritance. Alvarez (1992) suggested the idea of a "double helix" when thinking about the environmental effects and the biological inheritance in autistic symptoms. This describes the twisting "*around each other in interacting spirals"* (p187-8) and the need to see the interaction of one with the other.

Pozzi-Monzo in her later paper (2012) tells us that when there are failures in the attachment relationships, that is a failure to contain the infant's emotional experience, this inhibits their ability to become aware of their thoughts and feelings and therefore, infants may resort to coping through a hyperactive motor discharge. This is similar to Bick's second-skin defence.

Often it is one or two aspects of a child's development that is markedly delayed or disturbed that prompts a referral to CAMHS. Cathy Urwin (2002) writes of the significance and meaning of the particular element of language development. Delayed language is a feature in the diagnostic assessments of autism, as per her paper title, 'Autistic isn't necessarily autism', meaning that a common feature of autism doesn’t always equate to autism, but may be a delay that can be progressed. She explores how child psychotherapists can contribute to this sort of thinking and understanding of the meaning of the child’s difficulty and then how it may be most helpfully addressed. She writes:

> ‘*A psychodynamic viewpoint can complement psychiatric diagnosis by describing the nature of the child's object or part object relations that contributes to symptomatology, the ego deficits and their implications.*’ (p 91)

Orford (1998) describes the whirlwind sort of experience of the ADHD child in response to the usual ups and downs of life, and how these more ordinary events are felt by them in a far more extreme way. This may be indicative of the internal terror of uncontained infantile trauma. Her description of internal trauma reminds us that this can be in response to external traumatic events such as abandonment, parents’ drug dependence, experience of war, etc or something more relational and less obviously directly traumatic to the baby, for example a loss of a parent for the parent of the baby around the time of the birth. She references Allan Shore (1994) and Judy Shuttleworth (in Closely Observed Infants,1989) writing about the baby’s ‘…*sense of being gathered together*.’ This so succinctly describes the mirror opposite of the ADHD child who may be often described as ‘all over the place.’

As explained by Music (2011) often maltreated and looked-after-children are given neuropsychiatric diagnoses because their behaviour, at first glace, looks quite like autism, ADHD or conduct disorder. Music thinks about alternative ways of conceptualising the range of issues such children have in order to address them in different ways. Although he speaks of children traumatised through maltreatment, we can again conceptualise trauma through poor attachment relationships. Poor attachment relationships are not by any means always through intentionally neglectful or abusive situations, but can also occur through being cared for by parents who themselves have not had their needs met as children, or who are preoccupied with something psychologically demanding as we heard about from Maté (1999).

Reid (in Alvarez & Reid 1999) talks about Autistic Post Traumatic Developmental Disorder as a sub-type of autism. Through clinical observation, she has identified something similar to post traumatic stress disorder responses, particularly numbing and avoidance. She writes about a type of very early infantile experience that interrupts ordinary development that can be described as traumatic for the totally dependent baby. She hypothesises that this sort of child has had a traumatic experience that ‘seems to have activated an autistic response in a possibly genetically/biologically vulnerable child’ (p. 96). This suggests the idea of a combined aetiology of some autistic presentations. Indeed, Singletary (2015) describes the depth of possibilities around integrated factors that can lead to autism and highlights how neuroplasticity, both adaptive and maladaptive, can shape how children’s brains can develop, but also how they can be helped to manage difficulties associated with autism and neurodevelopmental difficulties. She reminds us of Perry et al’s (1995) work on how once helpfully defensive states of being, such as cutting off from a traumatic or depressed environment may become more set-in traits of how a person may relate, which then become more likely to be pathological. Further, Reid talks about trauma which originates with previous generations. The effects of trauma can go unnoticed, but silently pass from parent to child in various ways such as maladaptive ways of relating and epigenetics. Using her words:

> *'The capacity of any parent to provide a protective shield for their infant, and to contain catastrophic anxieties, varies from parent to parent, and for any parent will vary according to their own current resources.' (p106)*

Of course, these 'current resources' will depend partly on a parent's own childhood. Reid describes how linking their experiences with those of their child and thinking with them about the many internal and external variable at play, both in the parents and the infant, can help alleviate the guilt and responsibility that parents can feel.

As we understand the interplay of the infant's attachment relationships, parental trauma and relationship and the neurobiology of the infant, we may also understand the treatment of such presentations to require substantial parent input as well. Using Orford's (1998) words '*not only will children require a different sort of experience but parents and carers themselves will need help in the provision of a rather different environment'* (p.261). This is particularly important when thinking about clinical work with parents and their children, addressing both the child's and the parents' internal and external presentations, as guilt and blame can become barriers to productive work if they are not understood.

It is with these thoughts in mind that the following section will focus on how parents have been viewed by professionals in the past, and more recently, how clinicians and researchers have made deeper attempts at understanding the inextricable link between parent and child when considering psychological intervention.

### 1.5 Understanding of parents and how they might experience help from the point of view of psychological practitioners

Early theorists, such as Kanner (1949) and Bettelheim (1967), and their early investigations and hypotheses about the aetiology of autism often put parents at the heart of the cause. This led to quite a lot of problems around investigating relational aspects of difficulties associated with autism. The psychoanalytic community has had to work hard to consider the long-term effect of these early theorists and how to approach working with parents with the knowledge that blame is part of the history of assessment and formulation. Tustin (1981) wrote about primitive anxieties that prevailed due to a failure to separate or of an awareness of separateness that came about too early, before the infant had established enough of a sense of self to cope. Far from being emotionless or unrelated, these infants' experiences of relationships and emotions may have been overwhelming and so a retreat to something more cut off was employed as a protective mechanism. It becomes clear why clinicians might draw the conclusion that the pathological state was due to external failures, however, genetic or constitutional factors within the child were less in focus and certainly more time was needed to consider the interaction of these internal and external elements. Houzel in Tsiantis (2004) insists that we must put aside thoughts of aetiology and focus with parents on the meaning of their child's behaviour or communications. It is through this that a therapeutic alliance can be made and psychoanalytic work can be utilised.

Cleve, in her book entitled 'From Chaos to Coherence' (2004), describes the assessment and treatment of an adopted boy diagnosed with ADHD and writes about how these kinds of neurodevelopmental issues can affect emotional wellbeing in the child as well as the family. Cleve describes:

> '*The child's kindred usually suffer from the endless impulse outbursts and are distressed at not being able to live in harmony with their own rhythm. Instead, they find themselves in a never-ending state of stress. This, in turn naturally has a*

> *detrimental effect on the child. Members of the family are often cut off from a normal social life since their friends find it too exhausting to be around them'(p199).*

Margaret Rustin (in Lanyado and Horne, 2009) reminds us that '…*everyone in the family is affected by everyone else, the choice of whom to help is usually a mixture of pragmatics and resources*.'(p215). She informs us succinctly of the importance of sensitivity when working with parents:

> *'…knowledge and sensitivity can be used well in responding to parental anxieties, but it can also be a source of trouble. A degree of competition, jealousy and envy is likely to be evoked by professionals who try to help when parents feel themselves to have failed. Tact, humility and a real belief in the shared nature of the task are essential' (p218).*

Similarly, Klauber, in Alvarez and Reid (1999) writes about how imperative it is to think about the state in which many parents arrive at assessment and their experience during assessment and treatment. She writes in relation to the autistic child, but her points could easily be transferable to any parents who bring themselves and their child to the 'under the microscope' situation of the CAMHS consultation room. She describes how:

> *'Many [parents] are worn out, tired from too many sleepless nights, from gargantuan temper tantrums and the absence of limits and boundaries. They loose the will to establish parental authority or the imagination to envisage the possibility that they could. They feel that they are ineffective and of no significance to their child…Ideas about what is good for or bad for children, or why boundaries, limits and firmness in a very ordinary way are useful, are not there' (p35-36).*

Orford (1998) speaks about the commonality of some of the symptoms that make up diagnostic classifications for ADD/ADHD in many children for short periods of time during childhood, she reflects on the position of many parents who seek help:

*‘It is also these classifications that have caused the worried parents of many less seriously disturbed children to heave sighs of relief that these problems are not just the prerogative of their child but is shared with many, are actually recognised by professionals and have a name. ADD/ADHD is probably over diagnosed as a result.* (p254)

This seeking of a diagnosis and standardised treatment could be applied to parents, and perhaps professionals too, when faced with living and working with a child whose behaviour is disturbing. It also touches on the wish of clinicians to give relief; it is after all one of the factors that spur many clinicians on to work in such professions.

Bull (2020), reports on parents’ experience of their child receiving intensive psychoanalytic psychotherapy. Although this is not about assessment, it documents parent’s engagement with a psychoanalytic process of understanding their child’s behaviour. One of her conclusions was to give emphasis to the parents’ experience, even providing practical help first if necessary. This would be provided along the journey of understanding the internal landscape of the parent and with that, the related landscape of the child.

All the above cited authors illustrate the fragility of some parents who are finding it very difficult to parent their child. Parents may be affected by their own unresolved infantile conflicts or deficits in their parenting, mental health issues, relationship difficulties or trauma in their lives. It becomes clear how issues of guilt and blame can become again alive in the assessment room.

## 1.6 Psychoanalytic theory relating to the understanding of parents whose child displays pathological symptoms

Anzieu-Premmereur in Bronstein and O’Shaughnessy (2019) speaks about the challenges of being in contact with parents when engaged in child analysis:

> *‘Both parents could regress to their own narcissistic and Oedipal issues when they become parents, or when they are faced with an inconsolable baby, or an infant who does not satisfy their ideal. When the child shows signs of disorder, the wounded parent develops primitive defences. Paranoid attitudes and transferential attacks from parents are part of the work of the child analyst. The parents’ vulnerability to their child’s unconscious processes, and their sensitivity towards the child analyst’s intervention, can make the interaction between parents and therapist very difficult at times.’ (p108)*

Although assessment is very different to analysis, the immediate transferential situation when the child is showing some very worrying or difficult behaviours is possibly very similar. This reflection directs us to think about the difficulty for parents of both not knowing what is wrong and of feeling that somehow what is wrong may be their fault.

### 1.6.1Guilt, persecutory anxiety, and projection

The next section examines some normal but difficult elements of human experience that can, under certain conditions, increase in intensity causing a disruption in a more ordinary developmental pattern. An understanding of these powerful internal processes is key because of how they can present in situations such as the complex neurodevelopmental assessment. A thorough understanding of defensive mechanisms allows clinicians to understand behaviour that might obfuscate something underlying. By understanding these psychological developmental processes, we can understand the conflicts that parents can experience when thinking about their child's difficulties. The experience of becoming a parent, and of having difficulty with one's child can cause a lot of stress. Old psychological wounds or weaknesses can be reopened in times of stress and in parallel to one's child while he/she navigates though the same developmental processes.

Melanie Klein developed ideas around two types of guilt from an 'object relations' perspective culminating in a distinction between the two in 1935. We understand Klein's idea of an 'object' is that it is the subjective impression and experience one has of the real, external parents/carers through interaction with the self, rather than a more objective sense of them.  Firstly, an early primitive functioning seen in the first months of a child's life where part-objects predominate. A part-object is when infants are unable to conceive of their parent as a person who is multifaceted, imperfect and yet in most cases, reliable (Klein,1936). This gives the sense of something frighteningly changeable even in the very best of circumstances. The infant cannot manage the two or more experiences of their carer together and they are simply felt as changing from one to the other without retaining anything of the previous felt state.  Anxieties are of course extremely high in this position, and so aggressive, attacking and defensive retaliative manoeuvres feel critical to one's survival.

When considering children who are exposed to anxieties that they are not yet ready for, either by way of suboptimal environmental conditions or trauma, or because they have constitutions that lead them to premature ego development, we then have in mind a child who must employ defences that if persist, can inhibit brain development and psychological growth, or as Rhode (2018) puts it, *'…defence itself leads to deficit'* (p716). When we consider this sort of position, and the resulting intensity of the experience and sensation, we can also recognise the implications. The person, be they an infant or an older person in a temporary regression to a primitive state, may well experience guilt that can occur due to fear of retribution. The experience is one of being attacked and of attacking back. It is a highly paranoid state, during which ‘persecutory guilt’ is felt. Klein termed this state the paranoid-schizoid position (1946).

Klein’s second sort of guilt comes developmentally later, and is generally a healthier, more whole-object related sort of guilt. This is when the infant comes to know their parent or carer as more of a whole person. When they can retain a sense of their goodness, even when a temporary failure in care is felt. Depressive guilt (Klein, 1935) is a type of concern for the loved person when harm is felt to have been done. Klein describes the working through of this, to lead to reparation which is essential for future relationships.

Although an infant is expected to move from the paranoid-schizoid position on to the depressive position, Klein did later recognise that these positions can be revisited throughout life. She notarised this with a double ended arrow PS ⟺D signifying that they can be moved between.

Klein developed the concept of projective identification (1946) when the unwanted part of the self is directed towards the object but not completely split off from the self. The object not only fails to contain the projection but takes on and starts to own the unwanted part. The management of the giving and taking of these feelings would usually be the job that the primary carer who would process them for the infant and is what Bion (1962) termed ‘containment’. Britton (1989) suggested that if a child had not managed to tolerate and work through the terrible sense of loss and envy during the depressive position, a persecuting force may persist. This can affect the relationship with the external object – the parent and the internal object which then has consequences for the forming of relationships further down the developmental line.

In their seminal paper – Ghosts in the Nursery - Fraiberg, Adleson and Shapiro (1980) write of the '…*repetition of the past in the present*.' (p166) illustrating the broad effects that intergenerational relationships can have. Widener (1998) writes of treating attentional and hyperactive symptoms by understanding the complex relationship not only between the child and their parent, but of the parent to their parents too and the affect that this has on their parenting. She concludes that:

> *'…there is the need for increased therapeutic work with parents so that the parent-child relationship as well as the cross-generational dynamics between family members come to be understood and worked through. Childhood is complex, confusing and often painful for both the parents and the child we need to be humble in the face of the intricate map of interpersonal issues triggered for both parent and child at every stage of development' (p279).*

Widener came to this conclusion after recognising the increasing use of pharmaceuticals for children displaying symptoms of ADHD/ADD. She recognises the pressure and persecution felt by parents from their child's teachers and perhaps others, in regard to the objectionable behaviour. It is not mentioned, however, that clinicians can also feel pressure to diagnose. They of course want to help children and parents in distress but can also be subject to the intensity and ferocity of the 'ghosts' from the past on the present situation. Maté (1999) speaks of parenting a troubled child and how *'parental guilt, even if misplaced, is a wound for which the genetic hypothesis offers a balm'* (p48). A desire to alleviate this 'wound' may prompt clinicians at an unconscious level to give diagnoses.

Redirecting the sense of guilt is also important. Parents can feel angry, denied, even assaulted by clinicians who do not diagnose. The feeling of guilt and blame can be projected into the clinician which makes therapeutic work very difficult. If assessment is time pressured, superficial or if the projections from parent to clinician are powerful enough, there is the risk that diagnosis may be given without enough understanding of the relational aspects of the presentation. This of course can affect the treatment subsequently offered.

Symington and Grotstein (1993) write about the development of narcissism when there is great trauma. This internal defensive structure has been employed to protect a person from a deep and disturbing trauma and therefore is very difficult to alleviate as the function of the protective feature has been most vital. It is therefore necessary to be vigilant and cautious with such a state when working with parents *'the last thing a person wants to do is return emotionally to where it happened.'* (p73)

### 1.6.2 Living with uncertainty

There is a growing body of research as well as anecdotal evidence, particularly demonstrated by the use of online support groups, that show how parents of children with undiagnosed conditions or complex presentations struggle to live with uncertainty.

One of the most active groups is Harvard's Undiagnosed Diseases Network. This is happening despite the many clinicians - from different backgrounds and disciplines - who work with patients coping with unusual combinations of symptoms, searching for answers. Dr. Gail Jarvik, a medical geneticist at University of Washington Medical Centre describes how relieved parents can be once they receive a diagnosis, as they had been holding the sense that their child's problems were somehow their fault. It seems possible that the excruciating uncertainty may link with more paranoid ideation.

Bion (1962) wrote about tolerating uncertainty in the quest for knowledge. He described that to be able to sit with the uncertainty and learn from experience there needs to be sufficient alpha function. Alpha function is a concept he described to help us think about the tool necessary for conscious thoughts that could then be used to learn. In infancy, the primary carer must provide alpha function for the baby to bring thoughts and feelings into a framework for conscious thought. In infantile states of high anxiety, thoughts may remain at a persecuted beta element level when they are unthinkable and unable to be processed for learning unless another mind can provide alpha function in a transformative way.

Peter (2021) writes about the clash between using both medication and investing in psychotherapeutic work for children with ADHD. She speaks of the complexity of the aetiology of ADHD, but also of the difficulty parents and clinicians have with being able to conceptualise a more emotionally based discourse that might require psychotherapeutic rather than pharmacological treatment. Her investigation of a combined treatment package revealed more of a ‘marriage of convenience’ rather than a ‘truly fruitful partnership’. There was a pull towards the more powerful, experimental, evidence base of psychiatric practice, and away from the discourse that might question moral accountability. As previously mentioned, psychoanalytic practice has long been associated with parent-blaming and aligning oneself with a medico-neurological model might feel protective from that. It seems that despite the fear or discomfort of blame is not just in parents, but also strongly in psychoanalytic psychotherapists who are tasked with diagnosing and offering treatment packages for children who have an ADHD diagnosis which might include sitting with a level of uncertainty in the underlying causes and meaning of the troubling behaviour.

## 1.7 Staff group and individual processes

The focus of the previous literature has been on parents, however, the experience of assessment or any engagement with treatment always happens within a relationship with one or more clinician. This may be brief, but is often powerful. There is a wealth of literature examining work discussion groups, staff support groups, group functioning and social defences within groups and institutions (Armstrong & Rustin, 2015). To discuss these would be beyond the scope of this literature review, and so selected works which seem most relevant to this very particular setting of multi-disciplinary clinicians completing a complex neurodevelopmental assessment, and how their experience informs the assessment will be examined.

Rosenbluth (1970) draws together Freudian and Kleinian work with a helpful question that child and adolescent psychoanalytic psychotherapists regularly ask themselves '*What is the child doing to me at the moment, feeling in relation to me now?*' (p78). In therapy, this question would prompt interpretation. In work with parents, certainly in a short assessment piece of work, live interpretation will not often be used, but the question itself can remain as helpful as ever in understanding the underlying communication and possibly the reasons why. Child and adolescent psychoanalytic psychotherapists will have worked for years at their own psychoanalysis, on understanding the effect of long- and short-term relationships on them and how to use this to understand the people that seek their help. The primary tools of the psychoanalytic psychotherapist are the transference and counter-transference. Despite this thorough training, psychotherapists will not always be fully aware in the moment of the meaning of the impact of the families that they see on them during these brief assessments with a focus on the quick turnaround of a diagnostic outcome. Furthermore, clinicians from other disciplines may not have had the benefit of psychoanalysis or personal insight. The experience of meeting a family under great emotional strain and impacted by primitive processes can result in significant emotional experiences for the staff team as well.

Britton, in Box et al (1981), in his paper ‘Re enactment as an unwitting profession response to family dynamics’ recognises that Freud’s original idea of ‘repetition compulsion’, that is the reoccurring of situations or relationships, useful in psychotherapy or psychoanalysis as a medium for working in the transference, can also manifest in networks of professions. He reflects that urge to ‘repeat’ is very strong and that an element of discomfort, strain or anxiety is inevitable in the process of ‘realising’ rather than repeating. Staff teams or institution can be affected, and it is not easy to recognise when this is happening.

Pozzi (2000) cites Main’s (1957) paper looking at nurses’ use of sedative with patients with mental disorders. Main concluded that the sedative was used when the nurse could no longer bear the disturbance of the patient, rather than for the patient’s benefit. However, when staff were given the opportunity to talk about their feelings of frustration, aggression, guilt and despair, their use of sedation decreased hugely. Pozzi uses this to illustrate how we may clinically conceptualise a parent’s wish to have their child diagnosed and subsequently medicated for symptoms of inattention and hyperactivity. She describes how parents may wish to look towards a genetic or neurophysiological explanation of their child’s difficulties to avoid thinking about a sense of responsibility or feeling of influence of their own on their child’s problem. This could be due to unbearable guilt related to an unthinkable experience of self-blame, fear of being criticised by other parents or blamed by professionals. When the parent’s experience is so intense, this can be communicated through projection to the clinicians. This may put the clinicians under psychic pressure to comply with the wish to diagnosis and medicate if the projective mechanisms are not fully understood in the moment.

Zachary, in Armstrong and Rustin (2015), writes of the profound effect that patients can have on the staff that work with them, not just between staff and patient but within the staff group. Reflecting on the work of Isabel Menzies Lyth (1988) and Tom Main (1957), she says ‘i*t was seen that staff responses tended to ‘mirror’ the patients’ pathology’* (p178). When this can be examined, it can be very helpful, but when it is left unseen, it may obfuscate the clinical picture.

Chuard (2021) also speaks of the dynamics in multi-agency working with families and young people. He writes of Bion’s (1961) work on groups, of the potential for the group to be in ‘group work mentality’ where the group works towards its goal within the realms of reality and with rational reasoning. Groups can also be in ‘basic assumption mentality’ which is more instinctive and does not withstand scrutiny or evaluation. Finally, with reference to Canham (2002), he speaks of the ‘Gang state of mind’:

> *‘Individual differences between members cannot be acknowledged, as this would lead to conflicts and put the group in touch with painful ambivalent feelings and an awareness of limitations. A group which finds itself in this state of mind is unable to learn from experience due to the fact that there is a limited capacity to think about and process emotional experiences arising from the inevitable conflict in group life’ (Chuard, 2021, p21).*

Working groups may move from one of these levels of functioning to another within short spaces of time. Reflection and supervision, as Chuard (2021) suggests can be helpful in bringing awareness of the primitive anxieties that act upon us especially when under pressure. Of course, groups or ‘gangs’ can be made up of both clinicians and of family members, and so we can apply this understanding to both sides of the assessment process.

## 1.8 Conclusion

In conclusion, there seems to be a need for further and perhaps deeper investigation into the internal worlds of parents during the process of neurodevelopmental assessment. Many of the papers mentioned painful experiences of parents during assessment such as stress, uncertainty, persecution, guilt and a loss of a sense of control. One of the key features of many of the papers at the beginning of this section highlighted a desire to increase parent satisfaction and a reduction of distress during the assessment period. However, some of the later literature steers us more towards understanding the nature and meaning of the felt distress rather than simply alleviating it. Although this may be a more complex process, and inevitably more time consuming, it may also allow the relational aspects of the child’s difficulties to be more thoroughly understood. This may not change the overall diagnosis, but along with our increasing understanding of combined aetiology, it may affect how it is treated, both in a clinical sense and within the family and perhaps society.

There is a further branch of questioning that looks at the alternative to a neurodevelopmental diagnosis, which tend to be lifelong diagnoses. When there is a significant relational element to the problematic symptoms uncovered, how can families be helped to work to alleviate symptoms. It seems that by being helped with some of the internal processes identified here, such as feeling persecuted, guilty, blamed, or anxious while things are very unknown, may allow parents to embark on some therapeutic work which may make the wish for diagnosis less pressing. Some of the literature suggests that the therapeutic alliance is important, so further understanding of that could be helpful.

The literature looks at the interaction of the child and the parents from many angles, and at some aspects of interaction between clinician and parent. By examining in detail the experiences of the parents, and that of the assessing staff group, the research project of this thesis aims to further understand the experiences of the parent, the experiences of the staff group and how they might effect each other and the consequences for the child who has ultimately been brought for assessment.

# Chapter 2

# The Research Project Design and Methodology

## 2.1 Introduction

This is a qualitative research project exploring parents' lived experience of going through a complex neurodevelopmental assessment in a CAMHS clinic in a large city hospital. It aims to explore what it is like for parents to participate in the assessment.

Assessment and diagnosis for neurodevelopmental conditions is a complicated task. The aetiology for autism and ADHD as well as other conditions is not fully understood. Presentation of these conditions is continually being recognised in new and different ways. At times there may be queries over whether a diagnosis can or should be given and alternatives are often explored. This is an emotive issue for both clinicians and parents. Therefore, it was with this in mind that it was also decided that clinicians would be asked to take part in a focus group as well as interviewing the parents. The aim of this was to understand their experience and response to parents in the assessment clinic in order to better and more fully explore the research question of 'Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians*?* This happens by tracking what can be understood as a counter transference response. This means the clinicians' unconscious response to the parents' unconscious communication and defences. It is expected that this will be an additional layer of evidence to consider alongside what the parents have said.

Aspects of parent/child relationships are often painful especially when considered in the context of emotional, relational and behavioural difficulties often associated with autism and ADHD. Data collection was therefore designed to be in the recognised framework of the FANI method (Hollway and Jefferson, 2000). This method helps researchers to use a very open style of questioning, and to pay attention to the emotions, thoughts, anxieties and motivations of the participant, including both the conscious and unconscious dynamics and process. It also allows interviewers to follow the participants own narrative and to elicit meaning from it that may be as yet unknown or unprocessed by the participant. Hollway and Jefferson term this working with the ‘defended subject’. The interviews were then analysed with IPA (Smith, Flowers and Larkin, 2009) which has an idiographic philosophy, helps the researcher to analyse data in such a way as to keep the subjective experience of the participant at the core of its meaning while also allowing reflection on the researcher’s subjective interpretation of what is being said. Although this individual subjective position creates some problematic tension when applied to a focus group around a difficulty in extracting meaning for the individual, it also helped highlight tensions that come when thinking about a group that has to make a decision as one, as a team.

### 2.1.1The setting

The focus of the complex neurodevelopmental assessment of this specific CAMHS clinic isn’t usually on giving a diagnosis, rather exploring which direction to investigate further into or signpost towards. Therefore, although sometimes a diagnosis or conclusion is given, often there are further questions and the need for other investigative appointments. Cases that are complex, unclear or have multiple, sometimes interlinking aspects are the cases that are referred to this clinic. Families who are referred to this clinic have often been grappling with their child’s difficulties for some time. They may have been turned away by other services.

This is a clinic with a specialism and responsibility for the local neurodevelopmental pathway. If a patient isn’t diagnosed with a neurodevelopmental disorder, they are often referred back to their local CAMHS for treatment or alternative assessment.

A psychotherapist works using an understanding of how a service user makes them feel or act that can help illuminates aspects of how the person experiences the world, their preconceived ideas and relational patterns. It is known as a counter-transference experience. Within the assessment setting, it can inform us of the emotional and relational context which is significant in assessing particularly autism and ADHD, which are the most common neurodevelopmental disorders assessed in this clinic. The significance of this element is due to the often similar presentations of children who have autistic or ADHD like symptoms and those who have attachment or relational disorders. A child’s neural development is affected by their social and emotional experience and so understanding as much as possible about their emotional development can be helpful when forming a diagnostic trajectory.

## 2.2 Sample

### Parents

I aimed to interview six parents. I obtained verbal agreement and interviewed five. However, only four returned the necessary written consent form therefore only four have been considered participants for the present study. As documented in Smith, Flower, and Larkin (2009) IPA studies tend to have a small sample size and 3-6 participants provide enough data to allow for meaningful links, differences and similarities to be illuminated. They suggest that a too big sample is generally more problematic than one that is too small.

Inclusion criteria set to take part in the study were that they are parents over the age of 18 and of a child who:

- needed a complex assessment
- was between 7 and 15 years old
- not a patient of mine or due to be assessed by me.
- a fluent English reader and speaker due to budget limitation for an interpreter.

Clinicians

Three clinicians were recruited; A psychiatrist, a child and adolescent psychotherapist and a clinical psychologist. All were regular assessors in the clinic.

For inclusion, clinicians had to be part of the most recent complex assessment clinic at the time of when the focus group was held. The most recent case in the assessment clinic was chosen so that it would be fresh in the minds of the clinicians who see many families within short term assessments each week. The idea of interviewing the clinicians on one of the families that had taken part in the parent interview was considered, however, it was decided that this was not practical partly due to the time frame of the study. It would have meant interviewing clinicians on a case they had seen several months previously, and it may not have been remembered clearly. A further concern was around the ethical implications of presenting two sides of an experience given that the small data set makes it quite likely that the family would recognise themselves in the study and that this could have negative effects on links with the clinic and future engagement with menta health services. Lastly, it was considered that the possibility that interviewing the clinicians on a family that also took part in the parent interview would have swayed the research study into more of a case study lending weight to just one family rather than a small set sample. Certainly, it is acknowledged that both the small set of parents and the single clinician focus group has limited generalisability and is an example of what may happen which can lead to further study rather than conclusive evidence.

## 2.3 Procedure

### 2.3.1 Ethics:

I applied for approval from the Tavistock Research Ethic Committee. Approval was initially given on the 4th March 2020 (Appendix B)

Covid-19 adaptation

At the time the data collection was about to begin, the Covid-19 pandemic hit. This impacted the intended plan to recruit participants and an adapted proposal was submitted to the ethics committee. Covid-19 amendments to the procedure mainly supporting the use of video/phone interviews were applied for and approved in June 2020 (Appendix C). Further amendments regarding widened sample in age and approaching recently assessed as well as to-be-assessed parents were approved in August 2020 (Appendix D). Recent assessments were included also due to the far reduced number of assessments happening due to Covid-19 and the difficulty of remote assessments. This was an additional Covid-19 amendment made to the ethics committee.

## 2.4 Data collection methodologies

Data for this project derives from two different qualitative methods:

1) Interviewing parents

2) A focus group with the clinicians that regularly run the assessments

Below, the procedure of recruitment and of data collection for parents and clinicians are outlined separately.

### 2.4.1 Parents

#### 2.4.1.1 Recruitment

The Covid-19 adapted recruitment process for interviewing parents was as follows:-

The administrator who books in assessments asked upcoming and recent assessment attendees, who were still under the care of the clinic, whether they would be interested in taking part in the study. The administrator was able to give to the potential participants a very brief outline of what would be involved in taking part. If they agreed to be contacted, their contact details were made available and they were contacted by telephone by myself, the only researcher.  A total of eight were contacted and three either explicitly declined or did not return my phone message. The other five who remained interested were offered dates and times in the following few weeks and were asked to share their address or email address for a participant information leaflet (PIL)(appendix E) and consent form. They were told that they could email or call the clinic with any questions they had.

#### 2.4.1.2 Data collection

Each parent was given an option of phone of video interview. Those that requested a video interview were sent a zoom link a couple of days prior to the agreed time. All participants requested video interviews.

Those that did not join the zoom link after 5 minutes were given a single phone call to allow for technical difficulties to be overcome.

Once in the video interview participants were asked if they had any further questions. It was confirmed that each had received the PIL. Some requested for a paper version and a SAE to return the consent form rather than doing an electronic signature. This was facilitated. Four out of 5 interviewees returned their consent forms. The fifth participant was excluded from the data set due to non-return of the consent form.

#### 2.4.2.3 Interview schedule and interviewing procedure

Three main questions were devised (please see Appendix F for interview schedule) one for each of the areas of assessment procedure. These were around the reasons and route to coming to this particular assessment clinic, the experience of the assessment itself and finally the experience of the feedback portion of the assessment. The four interviewing principles of the biographical-interpretative method as discussed by Hollway and Jefferson (2000): open questions, elicit stories, avoid ‘why’ questions and follow respondents ordering and phrasing were kept in mind.

The interviewer reminded the participant of the aim of the study (to investigate parents’ experiences of the complex assessment). They were told the time frame of the interview (50mins) and assured that they could take their time and talk about what feels important to them. They were reminded that the interviews were going to be audio recorded and transcribed for data analysis purposes and that steps to protect anonymity would be taken.

As can be seen in Appendix F, it should be noted that the interview questions are followed by a series of prompt questions to be used by the interviewer, should the participant need them, but are not to be used exactly as written in structure or order but as per the need of the individual. The fundamental purpose of using this technique is to gain access to personal, non-intellectualised, unconscious, or unprocessed experiences. By allowing a high degree of flexibility within the interview schedule, the interviewer can follow the participant’s associations and not be restricted so much by any expectations or associations of their own.

At the end of the interview, participants were thanked and sent debrief sheet (Appendix G). Interviewees were verbally offered a further meeting in the form of an extended debrief or continuation of the opportunity to talk about their experiences.

All interviews were audio recorded and transcribed for data analysis purposes.

### 2.4.2 Clinicians

#### 2.4.2.1 Recruitment

Clinicians that regularly attend the clinic were asked for consent to join a staff focus group. They were emailed an information sheet (Appendix H) allowing several days for this to be read and digested before the date of the group. This resulted in the following group of staff: A psychiatrist, a child and adolescent psychotherapist and a clinical psychologist. Two out of three of them have worked together for many years in these assessments in ordinary in-person practice. At the time of the focus group, they had been trying to replicate the assessments through video work as best as they could. They are a mental health service based in a covid-centric hospital in the middle of the pandemic under huge institutional pressure.

On the day of the focus group, prior to the beginning, the consent form was requested from each participant. The researcher made herself available for any questions that arose.

#### 2.4.2.2 Data collection

A mutually convenient time was arranged and the most recent assessment case to that date was thought about during the focus group. None of the families who took part on the research were the focus of this group. Just one assessment was thought about in this single, one-off focus group. This is due to availability and time constraints of the clinicians and scope of the study.

The conversation resulting during the group was audio recorded and transcribed for data analysis purposes.

#### 2.4.2.3 Interview schedule

This followed the same pattern of the interview schedule for the parents, the questions that were used to elicit data from this group were based on the FANI technique, as clinicians may also be classed as defended subjects particularly within a group of professional peers (see appendix I for clinician interview schedule).

## 2.5 Audio recording

I recorded the interviews on a handheld voice recorder. I transcribed these myself partly to protect anonymity but also as a first step in familiarisation with the data.

## 2.7 Data analysis of parents’ interviews

I decided to use IPA (Smith, Flowers and Larkin, 2009) as well as benefitting from utilising ideas from the FANI method (Hollway and Jefferson, 2000). IPA has a more established set of guidelines for new researchers but is also adaptable enough to incorporate the aspects of FANI that I felt were fundamental to elicit and prioritise both conscious and unconscious aspects in subjects that may well be highly defended due to the sensitive and highly personal nature of the interview subject. I considered Thematic Analysis, however, IPA seemed more appropriate for an increased depth analysis of each member of the small sample, and an opportunity for more individual elements to emerge as well as whole sample themes.

Immediately after the interview I wrote some notes about my counter-transference experience of the participant as well as some of the key points of their narrative that stood out to me. Later I completed a pen portrait (Appendix J) for each participant as suggested by Hollway and Jefferson to both allow for the basic facts of the individuals circumstances, the detail of the individual narrative as well as keeping the gestalt of it to be recorded in order to enhance and evidence the superordinate themes that I will go on to describe in the following chapter.

As well as these pen portraits I wrote a paragraph for each participant describing my counter-transference experience and links to their facts of circumstance. This was to add richness to what is a small data sample.

I completed the following steps for each interview transcript.

1. Audio-transcribe interview into a word doc.
2. Re-read interview for familiarity
3. Write a pen portrait
4. Divide up interview into seemingly salient points or sense making chunks and transfer to an Excel doc. (Appendix K)

5. Add columns either side of the column containing interview transcript data
6. While listening to the audio recording, write initial and explorative comments including comments on aspects of counter-transference into the right-hand column.
7. In the left-hand column write ideas for emergent themes
8. List all of the emergent themes into a new word doc and move around to get some idea of the sub themes for the individual case. This was a fluid process and took some time and several adjustments (Appendix L)
9. Compare themes with pen portrait to retain both a gestalt perspective as well as taking into consideration the reflexive double hermeneutic of the participants' understanding of their experience, and the researcher interpretation in an attempt to make sense of it (Smith, Flowers and Larkin 2009)

Hollway and Jefferson (2000) remind us that the analytic task is to assist in the production of the [participants] voice not to assume the stance of interpreter which implies knowing better that [the participant].

## 2.8 Data analysis of the focus group:

The focus group was analysed in a similar way; however, it was found that there was a complexity around the epistemological idiographic ideology of IPA of illuminating an individual's lived experience when this is heard within a group rather than in a one-to-one interview. Although this had not been anticipated due to the researcher's inexperience, with reference to Palmer et al (2010) and Love et al (2020) who both comment on the use of IPA with focus groups and advocate for an adapted method, a further stage of checking and adjusting the findings was added in the later stages of the analysis. It is also be commented on in the discussion chapter. Palmer et al

(2010) stresses the importance of attunement to interactional factors. These included attention to the position of the individual's narrative within the group and the extent to which this was able to be heard by or suppressed by the group; issues of status and power within the group; length of time in the team; the relationship of the researcher to the team (as discussed below); and the manner of facilitation of the researcher during the group.

The themes produced were relevant to the assessing team rather than to individuals within the group. This focus was used as the assessing team must work together to give united feedback and recommendations whether or not they agree at the end of the initial consultation.  This seemed to support the notion of clinical validity bearing in mind the clinical applications that this study may suggest.

## 2.9 Researcher subjectivity

Hollway and Jefferson (2000) reflect on the impact that researchers can have on the representation of the voices of those that that study. They stress that it must be acknowledged that what researchers understand from the data, is an interpretation affected by their own experience, knowledge, understanding and motivations as well as many other things. It is also an important part of IPA to consider the double hermeneutic as described by Smith and Osborn (2003). This is a concept that describes the researcher making sense of what the participant says, which is the participant's own way of making sense of their experience, in this case of the assessment process and aspects of their child's history. As part of the 'pen portrait' as described in the FANI method, I wrote notes about my experiences and feelings towards each participant and how these developed over the course, not just of the interview but of the data analysis, as I transcribed and analysed their words and the wany we were in relation to each other. I have included these notes in the Findings chapter as part of the data to help draw together the idea of how people affect each other consciously and unconsciously and how this inter psychic experience unfolds. This can happen in any relational situation, but here we consider it in terms of the clinical assessment situation.

The motivation for studying this particular area was three-fold. Firstly, to understand the process of complex assessment and diagnostic experience from the point of view of those that often initiate or substantially contribute to the move to assessment and diagnostic services – the parents. Secondly, to contribute to investigating an ongoing complaint from the assessment team around running out of time to provide feedback to parents after the complex assessment. Finally, to understand more about the conflict that occurs when there is a strong drive for progressing towards a diagnosis from one party and a disagreement with this from another.

The second point came to light due to the researcher being in the position of trainee child psychotherapist in the clinic where the complex assessments are carried out. As part of the traineeship, observation of and participation in the assessment was possible from time to time. It was clear during this experience that the clinicians making sense of the lived experience of the child and the parent was central to the assessment. The focus group analysis could perhaps now be seen as a triple hermeneutic, the researcher making sense of the clinicians making sense of the participant's narrative. There seemed to be a point of dissatisfaction that was anecdotally reported by the clinicians regarding the experience of giving feedback, that there was both not enough time for them to give it but also for the parents to take it in, digest it and respond. There was also a difficulty in distinguishing neurodevelopmental disorders and emotional/attachment-based disorders and the subsequent meaning of these for the families attending the assessment.

The researcher, therefore, was motivated to try and untangle from the lived experience of both parents and then clinicians, something of the meaning of diagnosis and provision of services in relation to the assessment and/or diagnostic process. There was also a contractual dependence to the clinic and the clear seniority of the clinicians to the trainee/researcher. The clinicians and the trainee/researcher continued to work together throughout the course of the research project potentially affecting the expressed views of the researcher.

# Chapter 3

# Findings

## 3.1 Introduction

In this section, findings are presented related to the question posed at the beginning of this project: '*'Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians?*

The findings are divided into three main sections. The first one addresses the research question from the point of view of the four parents who participated in the study, reporting on the results which emerged from the individual interviews. In section two, the findings have been considered under the same research question but through the subjective and counter-transference experience of the clinicians involved in the assessment process, reporting on the results retrieved from the focus group. Finally, the third section is data relating to the researcher's countertransference experiences during the interview and data analysis process. This provides a further layer of understanding how the relationship between clinician and parent may unfold during short term assessment work.

## 3.2 Findings from the parents

From the analysis of the individual interviews, three common superordinate themes have emerged:

1. Parental trauma and the role in the child's difficulties

2. Difficulty, uncertainty and the development of epistemic trust
3. A persecuted state of mind: How assessment effects parental sense of self and clinician

The current superordinate themes across participants are drawn together but detailed specifically to each individual. In the description of each theme, subjective reflexivity of the researcher is used as a cornerstone for helping to understand the mood and tone of the interview, the meaning of the researcher's counter-transference during and shortly after the interview and the effect that this had on the overall interpretation of the data and production of the following themes. To help bracket the subjective aspect of the data analysis, the tool of writing pen portraits (Hollway and Jefferson, 2000) for each participant as described above in the methodology section has been used. An example of this found is the Appendix M. The themes that emerged from the transcripts of the interviews are then demonstrated with direct excerpts of the data. Finally, these excerpts are narrated with comments about how they were subjectively interpreted to support the superordinate themes that came to light from the analysis.

Under the heading of each theme evidence is presented from each participant.

** To maximise anonymity, the participants are referred to as P1, P2, P3 and P4 throughout the thesis. The researcher is referred to as 'R' within data excerpts.*

Below, **Table 2** illustrates some of the features of the pen portraits of each participant, as well as the sub themes for each that were developed from the exploratory comments and emergent themes that arose through conducting IPA on each of the interview transcripts.

**Table 2: Participants pen portraits and sub-themes**

All names and identifying details have been changed where possible to protect anonymity

| Participant | Key features of pen portrait | Sub-themes |
|---|---|---|
| P1 | • Father of young adolescent boy.<br>• Not British<br>• Already holding an ADHD diagnosis<br>• Hoping for a broader, holistic understanding and help with emotional and behavioural difficulties.<br>• Highly educated couple<br>• Much time and money invested in trying to get the right support.<br>• Narrative often told as if telling a fictional, dramatic story.<br>• Competitive and critical approach.<br>• Unhappy with quality and outcome of assessment | 1.Parents sense of knowledge in contrast to the clinicians' professional knowledge;<br>2.The processing of traumatic experiences and emotions;<br>3.Thoughts around aetiology: looking for external causes for the problems<br>4.Dissatisfaction non-confirmationary assessment. |
| P2 | • Mother of mid-adolescent girl.<br>• British<br>• Preconceived idea of ASD.<br>• Wanting confirmation of ASD to enable educational support.<br>• Professional single parent. | 2.The parent's self-perception (positive and negative)<br>3. Pathological diagnosis to relieve sense of guilt |

| | | |
|---|---|---|
| | - Suspicious and doubtful approach.<br>- Initially unhappy and fearful about depression diagnosis given.<br>- Happy with subsequent care received.<br>- Overly assertive and arrogant at times and extremely vulnerable at others. | 4. Experience of assessment being affected by past emotional experiences.<br>5. Parent's needs |
| P3 | - Mother of latency aged child.<br>- Not British.<br>- Wanted a diagnosis of ASD to help with an EHCP.<br>- Single, professional parent.<br>- A lot of time and effort had been put into trying to work out what was wrong and to find the right professional help.<br>- Desperate to say or do whatever it takes to get the help he needs.<br>- Frustrated at how long the process takes | 2.Being with the experience of not knowing<br>3.Ongoing injustice post assessment<br>5.<br>6.Unexpected emotional consequences of assessment |

| | | |
|---|---|---|
| P4 | Mother of older adolescent boy.<br>Not British.<br>Professional couple.<br>Wants autism diagnosis but not sure to what end.<br>Wants help for her sad, lonely son.<br>Wants help with her parenting.<br>Very critical at times, seems helpless and lost at others. | 1.Perception of the parent/professional power dynamic<br>Diagnosis as an attempt to cope with uncertainty3.<br>4.Emotional response to difficult parenting |

Table 3 shows how I drew together the sub-themes to form three superordinate themes:

**Table 3: Sub-themes to superordinate themes**

| **Superordinate theme** | **Subtheme** |
|---|---|
| **1.Parental trauma and the role in the child's difficulties** | • The processing of traumatic experiences and emotions;<br>• Experience of assessment being affected by past emotional experiences.<br>• Parent's needs<br>• Ongoing injustice post assessment |

| | |
|---|---|
| | - Unexpected emotional consequences of assessment<br>- Emotional response to difficult parenting |
| **2.Living with uncertainty and the development of epistemic trust** | - Dissatisfaction with non confirmationary assessment.<br>- Being with the experience of not knowing.<br>- Diagnosis as an attempt to cope with uncertainty |
| **3.A persecuted state of mind: How assessment affects parental sense of self in relation to the clinician** | - Thoughts around aetiology: Looking for external causes of the problems<br>- The parent's self-perception (positive and negative).<br>- Pathological diagnosis to relieve sense of guilt<br>- Parents sense of knowledge of their child in contrast to the clinicians' professional knowledge |

| | |
|---|---|
| | • Perception of the parent/professional power dynamic |

To illustrate the parents' experience within each superordinate theme, extracts from the interviews are presented with their relative coding reference which refers to the participant number, followed by the Excel cell e.g. 1.11B refers to participant one, cell 11B.

### 3.3.1 Theme 1 – Parental trauma and its role in the child's difficulties

This theme shows the diverse ways in which trauma was a common element in the life experiences of each parent. Using the word trauma in this instance relates to how something is experienced as described by the APA (2015) above. For example, a divorce or illness may be upsetting and yet not traumatic for many, whereas it might be very traumatic for those in whom it stirs up unresolved issues.

Interestingly, this theme seems to have mainly sprung out of the first question of the interview, which is 'Can you tell me about how you came to the complex neurodevelopmental assessment clinic?'. In planning, it aimed to enlighten the narrative of why they were there, what they hoped for or expected and how this connected to their actual experience. Instead in the participant's responses, specific traumatic episodes linked to the experience of and with their children come alive, intertwined with past experiences bringing a deeper intergenerational meaning for the participants as they meet the challenges they are presented with as parents.

For two of the four participants (P1 and P2), it seems clear that trauma was an element passed on from one generation to the next, giving a sense of how much it continues to be alive in the present and how this relates to the process and meaning making of assessment. For P3 and P4, instead, trauma comes more in the shock of the difficult situations they find themselves in and brings a sense of disorientation and bewilderment.

It can be seen how trauma comes again alive from the past in P1's narrative when he talks about a relationally traumatic aspect of his past:

> *'…but I did see some evidence here and there of my son having some OCD and that's because I have some history with my own younger sister, who has struggled with OCD for over 30 years' (1.11B)*

However, it is only at the very end of the interview that he is able to express more emotion regarding his experience of OCD (obsessive compulsive disorder) within his relationship with his son:

> *'[We tried] waiting a few seconds before he acts on the impulse, … and he tells me "daddy, no, I'm not gonna wait, because the urge is way too much for me to do this, so either you gotta take me away physically or I gotta do it"'. (1.80B)*

It seems that it is still very hard for P1 to be in touch with his own emotions, rather making me feel them with his effective story telling or keeping the emotionality to when he is speaking using his son's words.

Similarly, P2 also made reference to earlier experiences with a family member with health concerns.

> *'My dad was in the [NHS] system for a long time, wasn't treated greatly.' (2.44B)*

Being in the assessment stirs up memories for P2: she uses a stern voice suggesting a defensive stance. However, this information also suggests something of her experience of being parented.

P2 thinks about an aspect of her daughter's behaviour linking it to an important relationship. She attributes her relational difficulties to her belief that her daughter is autistic. However, in her narrative, this seems to be more about the effect of a bond being broken by her own mother when she left the country.

*'Things like with my family, she never made bonds with them… my mum left when she was four, she doesn't speak to her anymore.' (2.12B)*

Interestingly, P2 does not mention what this was like for her to be left as a single mother with a young child by either her own mother or the father of her child. Like P1, the emotionality related to difficult, relational life events for herself is not expressed, indicating an experience of relational trauma, and a possible projection into the child.

Even if in a less in-depth way, the assessment process also triggers memories of a relational trauma for P3. She speaks a little about her relationship with her child's father from whom she had separated from at the beginning of their son's difficulties, and she makes the following comment about the assessment report.

*'…it said in the report 'mother reported …' so for me to receive that as a report was a bit weird. My ex hates me for that… [laughs] even more. Because he said that I fed them with the information.' (3.21B)*

Her laugh that follows was chilling and I thought it could have easily spilled over into tears.

As well as past relational trauma, parents often spoke about more recent events that might be considered ‘event trauma’.

P1 talks about the two traumatic experiences he has had with his son. He reports:

> *‘The next day he woke up and his left eye was crossed. So now were freaked out. We take him to the emergency… A&E at [large teaching hospital] and I can tell that they’re freaked out.’ (1.19B)*

P1 then recounts his son’s second traumatic event: a serious head injury while playing at a friend’s house. During this narration I audibly gasp at one point and note the intentional dramatisation of his narrative and communication of the trauma. He described shock, trauma and possibly a feeling of guilt that they were not present when he hurt himself.

P2 also talks about a traumatic incident that seems to be somewhat of a crisis, however, she obscures this with her calm tone.

> *‘The way that she[daughter] got help now, is erm, unfortunately, through social services. When I was working as a teacher, I was stressed and it got to a point… I managed to get her counselling in school. The way I got it was when she eventually cut herself. … There was one or three occasions when she cut herself. It was more scratching herself with a bread knife… one morning when we had an altercation and social services were involved, and that’s now where some more help has come through.’ (2.14B)*

In this narrative P2 seems somewhat anesthetised to such seemingly frightening and overwhelming events.

In the following extract, P3 also speaks of an anxiety provoking experience:

> *‘We realised there was damaged vaccination in Turkey, which was given to a few 100, 000 babies, and [son] has received two doses of that. It had a massive recall, now the government is shutting all routes.’ (3.7B)*

There are linguistic factors such as sighing, pausing, deep breaths, emphatic words (‘massive’, ‘all routes’) and laughs that contribute to her narrative of this being a seemingly traumatic experience.

Three of the participants (P2, P3 and P4) reported in different ways their deep pain in seeing how their children were living their relationships with others. P2 explains:

> *…she (daughter)would love too hard, not recognise signs of stop holding my hand or stop hugging me now, it’s all too much and being able to form like lasting friendships. … (2.12B)*

She pauses and sighs, her tone is flat and there is something sad about her recount of this memory as opposed to the very critical and sure of herself stance that she takes at times; evidencing her daughter’s difficulties is necessary in the assessment, but it is also painful.

In the following excerpts, P3 grapples with her very painful experience of seeing her son struggle in the education system:

> *‘So again if I need him to be in this system, I just need him to have a supportive environment, because the outcomes of him being in the wrong way in there it was just as lot of anxiety, nightmares, tantrums, erm, it was heart-breaking.’ (3.16B)*

Similarly, P4 speaks of her son’s experience of his peers at school. She is less clear about what would help him and how it relates to the assessment process. She is slow and ponderous in her speech and her sentences are fragmented as if she is using the time of the interview and perhaps the assessment as well, to process what has happened in the family.

> *'…socially he doesn't have a lot of friends, he looks like a little bit weird… everybody is always picking on him. It is very painful as a mother…some bullies need to find a child… they are always finding him…' (4.22B)*

She reflects on her and her husbands' more ordinary adolescence. The assessment seems to provoke in her a question about why her sons are so different to them and a desperate wish to ease the struggles.

In summary, all participants were affected by traumatic experiences of at least one sort. Two (P1&P2) reflected on traumatic relationships in their own histories. P3 alluded to something quite traumatic about the breakdown of her marriage during the period of her child's difficulties. Three of the participants (P1, P2 and P3) spoke of events in their child's life that could certainly be described as traumatic to both them and/or the child. P1, P3 and P4 are not British born and therefore coping with raising children outside of the state (NHS, education, local authority) and cultural systems that they themselves grew up in. All of the parents found aspects of parenting their children with additional needs emotionally disturbing and relationally traumatic seeing them struggling at school and with their peers. It seems that there is both importance in what they experienced as well as how they as constitutionally individual people processed and reacted to these experiences.

### 3.2.2 Theme 2 – Living with uncertainty and the development of epistemic trust.

This theme examines how parents spoke about their thoughts of what it would mean to move from a position of not knowing what was wrong with their child, to something more enlightened or certain. For some, particularly P4, the idea about whether a diagnosis would provide this is questioned, for P3 and at times P2, it is felt to be the very focus of what they wanted and feel they needed.

P1 focus seemed to be to have someone's help in making sense of the '*huge thick file'* (1.B76) that they have on the son. He describes an incident where his son has a severe concussion. After telling me in detail about the event, he slows to describe what happened after they were discharged from hospital:

> *'For the first week, which is understandable after a concussion, all he wants to do is sleep, … but now he's got some very weird OCD signs…now the OCD is very severe all of a sudden.'(1.32B)*

He seems to be describing sitting with something very unknown. It brings to the fore the question about whether this is just to do with the brain injury, or if there is something more to do with the mind of his son, struggling to make sense of his son's worrying presentation.

P1 reflects on a previous experience:

> *'And from my sister's experience (of OCD)… in America they call it… it has the poof effect, all of a sudden it stops working, they don't know why…'(1.86B)*

There is a wish get more immediate help with managing behaviour and symptoms, but also to receive some understanding of the anxiety of living with uncertainty and unpredictability.

Unlike P1, P2 arrived at the assessment clinic with a degree of certainty that her daughter's symptoms were autism. However, the assessment did not go as expected:

> *‘…before I knew what was happening, they turned around and said that she was depressed… We don’t suspect any autism. Great. I was a bit wrong footed by that one.’ (2.25B)*

As voiced in the extract above, this information does not bring her any relief, quite the opposite. At this point the uncertainty and persecution is located in her family members:

> *‘I’ve had my family say, ‘oh you’re making things up, there’s nothing wrong with [daughter] she’s fine.’ So, there’s that thing of are they going to put it all down to her situation, coz there was a lot of stuff about her dad coming out. That’s in sort of in the back of your mind.’ (2.31B)*

This experience sounds unpleasant and accusatory, but perhaps also suggests something of the discomfort of living with uncertainty.

However, P2 described the development of a containing relationship when the initial assessment was extended with some individual sessions between the psychotherapist and the child.

> *‘What I watched most closely, is [daughter], where she is and where her mood is, and at the moment you know by the grace of god she’s ready to go through the school gates, which I didn’t think was going to happen.., you know there’s so much growth that she’s gone through this period you know, and she feels it and I can see it in her as well, so for me you know, I’m just so grateful...’ (2.48B)*

The parent is joined by the psychotherapist in a state of not knowing, but in a containing way.

P3 explains her experience with other NHS services before coming to this assessment clinic:

*‘I tried to take him to speech and language therapy through the NHS, I think we’ve been there twice and discharged.’* (3.6B)

She ends with a laugh, one of several throughout the interview, which seemed to express something of her incredulity, frustration and anger of continuously being let down by the health system previous to the assessment.

P3 at first describes the ongoing uncertainty even after diagnosis:

*‘I wish there were more follow up, I really need their advice, and they refused … so it seems like there is a lot of stuff still hanging in the air.’* (3.11B)

Her voice changes at this point. It had been calm and warm. At the end of the paragraph her voice wobbles suggesting she might cry at the frustration of the continued uncertainty both in definitive diagnosis and how she would get the help she wanted for her son.

She returns to her positive stance only by describing her feelings after hearing that the clinicians agreed with her concerns:

*‘I was crying in that meeting when they said it, because it was receiving the reassurance that I wasn’t just imagining it…’* (3.12B)

Her speech is full of pauses, it’s not carefully thought through, but more emotional. She can, at this point, be in touch with the ambivalence of a diagnosis when experiencing some containment through an experience from the clinicians of being listened to and acknowledged.

Finally, she expressed a sense of wanting to know, to gain some certainty through knowledge:

> *'…just put a name into it, then we can read about it, learn about it, getting the right help for him…' (3.27B)*

Similarly to P1, P4 brings her son who already has an ADHD diagnosis. She speaks about her relationship with diagnosis for her twin sons, one of whom has had the complex assessment in question.

> *'I have twins, yeah? One is diagnosed already with autism, and this one, he's diagnosed with ADHD but there is always some doubt about autism there… to me it looks like sometimes he's more autistic than the other one. I still have my worries, I'm not sure about the diagnosis.' (4.8B)*

There seems to be a thought that the complexity of twins, both with neurodevelopmental conditions isn't known. Doubt is very pressing here as she continues to reflect on an experience when even a paediatrician wasn't sure. There is the sense that no one can really be trusted to help her and that the uncertainty of diagnosis and treatment remains a concern to her:

> *'…it's not really clear what next. In Turkey, you go and when you finish the meeting with the doctors … you get a letter immediately and … And here it's like it can take a year before I can hear anything, oh, what now, they've forgot about me?' (4.17B)*

She goes on to think about the meaning of a diagnosis. It's a painful moment when the doubt becomes located in why she might need or want one rather than if her son qualifies for one.

> *'….I have been struggling with myself, does he need this diagnosis or …I think maybe with this title it will give some relief or understanding or we will know how to… someone will give us some help or help him…' (4.21&22B)*

In the next excerpt P4’s doubt is contrasted with certainty. Her tone is lighter and more wistful:

> *‘I remember when I watched Super Nanny and she explained erm, how to put kids to sleep (laughs) and I watched it so… I followed those steps because I understood exactly what to do and how to do this, erm, and then it was like a miracle...’ (4.27B)*

There seems to be no doubt in Supernanny’s precise method which is comforting in the face of so much complexity and uncertainty – there is a wish not for something that made sense of difficult behaviours, but that simply worked without answering or producing questions.

In conclusion, P3 and P4 talk about the diagnosis as a way of getting the right educational or emotional support for their child. For P2, the type of diagnosis seemed to matter more than what sort of help it might elicit. P1 seems to be seeking someone to work alongside with ongoing uncertainty. There are significant threads of coping with uncertainty in all of the participant. A diagnosis did not always help much with feeling more certain about how to help their child.

Within the uncertainty, there seems to be an element of wondering about their contribution to the disorder that unsettled parents and a strong wish for some confirmation that they weren’t somehow to blame. This is something that will be examined in the next theme.

### 3.2.3 Theme 3 – A persecuted state of mind: how assessment affects parental sense of self in relation to the clinicians

This theme illustrates the interconnections between the participants sense of self and identity and the meaning that a diagnosis can have for them. These were expressed in terms of their sense of responsibility and agency, how they felt seen by the clinicians and their reactions to this. Indeed, this theme gives a sense of how each participant engaged with the clinicians, how this was affected as the assessment progressed and then again at the assessment outcome. It also illuminates something of the relationship they have with their child.

P1 gave me an impression of some of the elements of his professional identity by using technical language in conversation with me, using most of the time a confident, critical tone of voice. His professional identity was also used as a defence when he felt criticised and misunderstood during the assessment. For instance, P1 describes how he and his wife planned to give their son minimal notice of the assessment. They attend the assessment with him still in his bedclothes as he refused to dress, to let the clinicians see how he really is. He is surprised that the clinicians objected and feels criticised. Later he speaks about not being able to behave naturally in front of the clinicians.

When he talks about the feedback portion of the assessment which comes after a short break after the assessment, he complains:

> *'We weren't impressed. It was not something that we have not heard 150 times before. …once they met and saw us more they would realise that their assessment is totally wrong.' (1.63B)*

P1 expresses feeling misunderstood. He is angry at this point; the assessment is not meeting his expectations or wishes. There is an impression that there is little dialogue or discussion with clinicians, but an expectation that with more time they would realise their mistake. It seems as if someone has to be wrong for someone else to be right. This seems to push him to bolster of his sense of knowledge and expertise by mentioning his PhD to perhaps feeling as more equal with the clinicians.

He returns to his highly critical stance:

> *' Like you always hear, it's always the parent's fault until they realise it's not the parent's fault, the parents have been listening to the experts.' (1.74B)*

This seems to be in retaliation to feeling blamed when they are told in the feedback portion of the assessment that they are not 'tough enough'(1.64B) on their son and need 'parenting lessons'(1.75B). There is a very critical part of him that is seeking an external target in response to unbearable guilt.

There was also a focus on the Englishness of the other in comparison with himself and his wife's identity of non-British when he said:

> *'We saw the English People and the English systems as too suffocating.' (1.9B)*

It's interesting that he uses the word suffocating. It suggests a restriction on breathing – a threat to life. The emotional experience of assessment sounds like it could have been extremely intense and possibly felt very threatening to him.

However, his confident, critical tone recedes a little and he appears less defended when he speaks about his experience in relation to his son's difficulties and a worry that he played a role in his condition come alive. It seems that there is a concern that he may have passed on a trait, either genetically or relationally.

P2 gives an impression of her sense of identity when speaking about her profession and experience and how it gave insight into autism's presentation when she says:

> *'I'm a schoolteacher so I've come across, and I've got friends who… erm, and well autism's everywhere now, but anyway, I kind of have always had an understanding of it'. (2.9B)*

She seems confident and sure of herself, although her hesitation suggests this may be not the full story.

It seems that she was hoping for the assessment to agree with her preconceived ideas. This not being the case, affects her significantly as shown in the following excerpt:

> *'To be told 'oh no, it's not there' it was just like, wow, and it hit me like a tonne of bricks…. I felt like a complete failure, I started thinking of all the things I'd done wrong. I remember I completely backed off from her…' (2.42B)*

She is in touch with an idea that she could be to blame for her daughter's difficulties, that a diagnosis of depression feels to her to be more guilt inducing than something neurodevelopmental. She backs away from her daughter, perhaps feeling that she has done or could do some harm to her.

P2 talks about her sense of diagnosis in relation to how a different decision was then reached after the clinician offered some sessions in relation to depression:

> *'… anything to do with autism got pushed to the side. It was clear that these sessions were targeting low-level depression… And then after they had had the sessions, which doesn't make me feel great, [clinician] came back to me and this is actually when we bonded, I saw her as more human… she said that after all the sessions she's had with [daughter] they are now going to consider ASD too…' (2.40B)*

There seems to be some relief at working towards a deeper understanding of her daughter together with the clinician. A sense of control seems to be important to her, but perhaps most importantly someone taking her point of view seriously. This experience brought to the forefront of P2's mind a very early experience in her daughter's life, which she feels it mirrors for her a very similar experience to the assessment:

> *'…it's ironic, that when she was born… she was in special care. She had a lumbar puncture without my consent, and some days later she stopped breathing, and the same doctor that was really rude and arrogant towards me did the resuscitation. I remember that I was so angry at the time and I was going to complain and then he saved her life … It's a complete reflection really, I never thought that until now.' (2.52B)*

In both life events, alongside some negative experiences and feelings, there were also conflicting ones of gratitude towards clinicians who at first gave her an experience of not being taken into account in relation to her daughter's health.

The experience of not being taken into account, reverberates also in P3 when she seemed on the verge of tears at times perhaps caused by humiliation, rejection and not feeling worth being listened to when she first sought advice in other services. In her case the assessment then seems to restore her self-confidence. She can then own the doubt in herself a little more when she speaks of questioning her thoughts about her son:

> *'…it was receiving the reassurance that I wasn't just imagining it…'(3.12B)*

With regards to the assessment outcome and feedback, she says that she would have liked more detailed, specific advice:

> *'it's just for me, it's me… its nothing against them…'(3.18B)*

She seems to take the criticism on herself, suggesting that she is asking too much - being too demanding.

P3 describes how self-doubt returns to some extent even after the initial reassurance of the assessing team's conclusions:

*'I would like to see more in the report of things that they observed and things that they thought. I think they would give me peace of mind to think that I'm not just crazy or me… that it's hard for me to do stuff with him.' (3.22B)*

There remains a feeling that it could be a deficit in her or in her relationship with her son, indeed this restored self-confidence, sits alongside with being in touch with a feeling of not being good enough for her son, when she speaks about how she feels that home schooling would suit her son better, but that it wouldn't suit her. Her particular laugh alongside an earlier decision of how very difficult her son finds school betrays something of a conflicted stance.

P3 positive experience of the clinicians undertaking the assessment, is clearly shown when she describes how their supportive, understanding attitude made her feel. Her voice conveys something of the feeling of emotional support that is difficult to put into words when she says:

*'…I just felt they were there for me.' (3.25B)*

The positive experiences where she felt valued and understood the allowed her to keep such reassurance and security from the team within herself and use it in discussions with her son's school:

*'I was feeling so good with myself, the SENCO, she kept telling me you need to work on repetition with him … and I said no. I need him to feel confident and relaxed… after we received the diagnosis, I said to her you see, he doesn't need repetition.' (3.26B)*

She clearly states the confidence that the assessment experience gave her in negotiating his educational support and of the feelings in herself that came alongside.

Similarly, to the other participants P4 also mentions her profession in response to hearing about this research project. Again, it seems important that she establish her sense of identity as being linked to her profession as well as a parent.

Contrary to P3's experience, it seems that the assessment, the ruling out of autism and the lack of connection with a clinician has caused her to feel rather powerless and lost. There is a sad tone in her voice as if she has lost confidence in herself. There remains a sense of something innate missing in herself in her identity as a parent, rather than something that might grow and develop with some help:

> *'Sometimes I'm feeling like, you know, some parents have it naturally, and I'm thinking, maybe I'm not… maybe I'm lacking some parenting skills, that doesn't come naturally…' (4.23B)*

However, at the very end, there also seems to be a thought that it could be instead the professional advice that's faulty or it could be her inability to use it. Both of these views seem to suggest someone is to blame. Efficacy in P4 seems to be very low with a non-diagnostic outcome.

P4 described a moment of the assessment where she felt the clinicians were not seeing her son wholly literally, but also in reference to the complex spectrum of autism when she says:

> *'Just a short conversation, especially zoom, when you see just half of the body, that they can't see that [son] is just sitting all the time, and his leg is like this (demonstrates rapid movements) …so to me it was weird that this is the way to*

> *diagnose and to come to the conclusion that…You know the spectrum especially for autism is really wide and not everything is like the classical.' (4.12B)*

She has no sense of the clinicians getting to know her son and his individuality or them using her knowledge of him in their assessment. There is not much epistemic trust in the clinicians' decision which increases the uncertainty she was already experiencing in herself and in her parenting ability.

She speaks about her surprise at the outcome of the assessment:

> *'I thought it was just to meet us and to understand and then to come up with suggestions what to do but not to diagnose so at this point, I didn't know that it would be so clear. I thought they would say ok we need to do X, Y, Z. And, erm…then they came with their conclusions.' (4.19B)*

Her term 'suggestions' suggests a more iterative and collaborative process. Again, there is some passivity in P4, this time in relation to her connection with the clinicians. She doesn't seem to feel as if she can have a valued opinion alongside theirs.

All participants mention their professions in their interviews. This suggests that identity and how they feel about themselves is important to these parents, but also how they feel in relation to clinicians. It is a part of their identity that is separate to that of being a parent to a child with ongoing difficulties.

There are a number of times when participants look inwards to some extent and seem to consider that they might be a cause or part of the cause of their child's difficulties. All of them seemed destabilised at this though and employ various ways of coping with it. The importance of epistemic trust when examining a child's difficulties in the complex context of a family, particularly when there are traumas of various kinds that may have contributed to the current state of need is evident. It seems that some of the parents with memories of being dismissed in the past, linked them with similar feelings in the assessment. Parents' sense of self and their sense of the clinicians seem to be particularly important to think about, as the results above show, it affects how the parent might engage with the outcome of the assessment and what steps they take next.

### 3.3 - Findings from the staff focus group

As described in the methodological section, during the focus group, the clinicians were asked to answer the questions in relation to a specific assessment that they had run in the clinic. The analysis of the focus group retrieved three main superordinate themes common to the experience of each clinician during the assessment which are listed below. These themes will be described and then later discussed as to how they might stem from the unconscious communications within the assessment and how they go on to affect the clinicians behaviour and decisions

1. The clinicians experience of knowledge and power
2. The presence and management of parental trauma in the assessment framework
3. The need for time in processing conflict and coming to a conclusion

Table 4 below shows each of them in relation to their relevant subthemes

| Superordinate themes | Sub-themes |
|---|---|
| 1. The clinicians experience of knowledge and power. | • Defending against critical feelings.<br>• Being felt as judgemental<br>• Sense of disappointing the parent. |

| | |
|---|---|
| | • The experience of parents taking the course of least resistance.<br>• The discomfort of a power differential.<br>• Can there be disagreement in the group?<br>• Self-doubt in assessment.<br>• Is the team a 'working group'?<br>• Who digests the information and when?<br>• Projection of blame. |
| 2. The presence and management of parental trauma in the assessment framework. | • Parent is central.<br>• The difficulty of processing grief/regret/trauma<br>• Diagnosis as a way of appeasing feelings.<br>• The complexity of interlinked parent/child difficulties<br>• Discomfort of having to address attachment problems.<br>• Dilemma of how to approach conversations: quick and detached or slow and painful.<br>• The emotional cost of doing complex assessments where you can't offer treatment<br>• . Feelings of helplessness/hopelessness. |

| | |
|---|---|
| | • The experience of considering not good enough service.<br>• Difficulty of facing the unexpected in an assessment. |
| 3.The need for time in processing conflict and coming to a conclusion. | • Facing the reality that assessment, let alone treatment takes a long time.<br>• The necessity of time when addressing complex trauma.<br>• Limited discussion time minimises the possibility of differing opinion<br>• The illusion of agreement<br>• The challenge of dissent in a team<br>• The experience of mismatch of what the parent wants and what the time can offer.<br>• The extraordinary pain of seeing intergenerational relational trauma. Can anything we do be useful?<br>• Time to think/consider is felt to be unsettling<br>• The difficulty of thinking AND feeling whilst in a group with limited resources.<br>• The wish to know - to have a clear explanation. |

### 3.3.1 The clinicians’ experience of knowledge and power

This theme describes the discomfort that the staff members seemed to be feeling with this particular family where they had a preformed idea, which was then corroborated in the assessment that they could not give the child the diagnosis that the parents hoped for.

The psychologist in the team described her sense of the mother:

> *Psychologist: ‘There was a sense that she (the mother) was quite veiled in her emotional… kind of what she was revealing.’(FG.3B)*

Having the sense that an aspect of experience was being hidden made the psychologist feel uncomfortable, as if it could not be mentioned and yet was important. There was some knowledge she had about something that was trying to be hidden leaving her with a dilemma about what to do with it.

The psychotherapist noticed that there were cultural and socioeconomic differences between the family and them as a group of clinicians and thought about why it might be that the emotional aspect of the experience was being hidden. The idea that the parents and the clinicians could not work together with a degree of honesty and transparency, perhaps partly because of these differences, seems to pain the psychotherapist. Again, there was a sense of not being able to speak about certain things.

> *Psychotherapist:’ I think she wanted a diagnosis that would explain why they are struggling so much with this boy’s behaviour’ (FG.20B)*

> *Psychotherapist: 'It feels like being pushed away when we do those assessments you have a contact, they tell you an awful lot about themselves, it's a very intimate experience, and we say no sorry you go back to your local service.'(FG.23B)*

The psychotherapist speaks as if they are the one being 'pushed away'. Again, this seems to demonstrate the power of the counter-transferential experience – it seems unbearable for the parents to face the truth of their child's difficulties and its unbearable for the clinicians to voice it. The psychiatrist seems to also struggle with this outcome, albeit initially in a less emotional way. The clinicians become more annoyed with the referral system and feel as if this family should never have been seen by them. However, later on they speak about feeling left holding a 'crying baby' when the other team members leave them alone with the family. This shows more of a sense of an emotional impact that they might initially be defended against.

As they expected, they assessed the child as not needing further neurodevelopmental investigation which means that they would be referred out of the service. The psychiatrist conveyed a sense of the feeling of inevitability and dissatisfaction. There does not seem to be any sense of having been productive or of having been helpful in their assessment. They have not been able to give the parents what they wanted, but nor have they been able to use their knowledge of relational trauma to deepen the parents understanding of their child's difficulties. The parents' projections paralysed the clinicians and limited how they could have worked to understand some of the emotional complication of the situation. This all happened in an unspoken way, within the transference situation.

The psychotherapist gives a broader institutional sense of the sort of power and responsibility that they are left with. They use the institution's budget as a representation of how much is expected of them with such little resource, and the outrage this leaves them with:

> *Psychotherapist: '[the clinic] get paid something like £130 for the whole assessment. Which is ludicrous. So actually, to change the format and give it the time that we believe it needs… we just can't justify that.'*
>
> *Psychiatrist: 'Well, we cannot, but no one seems to be very interested in changing it, so why should we worry about it. Why don't we, prioritise the patient's need as opposed to the organisational needs.' (FG.30B)*

The psychiatrist takes an alternative view of where the power lies and what it means to have value. They move away from it being with the commissioners and consider what it might mean to spend as much time as needed with assessment cases rather than the absolute minimum, never mind the cost.

The team speak about their thoughts after the actual assessment:

> *Psychiatrist: 'Normally I will finish the letter and it goes. Now it's in the system not being sent, needing another thing in order to sugar-coat the information. It really doesn't feel to me a very satisfactory closure.' (FG.B25)*

The psychiatrist speaks about not sending the letter that give the outcome of 'attachment problems'. There seems to be a conflict about how to best manage the feelings of not being able to help this family and how best to manage the parents' feelings.

> *Psychiatrist: '…for them they felt that they'd done enough and they'd made a bedroom for [son] and they… you know… but that's not really what attachment is about, so that's the conversation, that's the bitter pill.' (FG.B35)*

Both of the above excerpts use the metaphor of the difficult-to-swallow bitter pill, which has to be sugar-coated. There is the imagery of something getting stuck in one's throat which seems also to describe how difficult it is to talk and digest thoughts about what it means to get a diagnosis of attachment difficulties rather than autism – the feelings, perhaps guilt and persecution are too much to take in.

There are thoughts about the neglectful power of the institution but it also comes to light that there is something unwanted about the power their knowledge brings them. This was elucidated by the decision regarding who in the group will take the responsibility of following the decision up with the assessed family. Indeed, the data shows how the responsibility to deliver unwanted news to parents with a difficult past is very disabling in this case. There is a sense of no one being able to talk about the very difficult reality of the situation and it is both painful and perhaps a relief that they have to refer the family to another service. There is power in their knowledge of recognising a relational difficulty but they keep to the task of ruling out a neurodevelopmental condition.

### 3.3.2 The presence and management of parental trauma in the assessment framework.

Similarly to the parents' theme 1 above, parental trauma is striking in this case. What seems difficult to grapple with is the reverberations of long-ago trauma into the present-day experience of parenting, which also reverberates within the assessment process. Clinicians find it painful to discover that parental trauma partly underpins the child's difficulties and that it is the parents who primarily need help. This is a difficult topic to address and not wanted by the parents. The conflict stirred up by this awareness affects the teams functioning.

> *Psychiatrist: ‘This was one of the most difficult cases we’ve had, one of the ones that we think are attachment, but it’s very difficult to raise the issue of attachment in the parents, because there is always the idea that it’s something to do with them. And they are locating all the difficulties in the child’(FG.8B)*

There is a slight hint of annoyance or blame in the final sentence, recognising the location of the difficulties and disputing where the help is really needed.

There is the acknowledgement that to get to think productively about the difficulties of the child, first the parents’ issues need to be addressed.

> *Psychotherapist: ‘You know we were all aware that there was this enormous thing, these experiences of mum’s… there was so much emotional content there, that our assessment in the way that we did it couldn’t tackle that. So, we were trying to address something that actually was a much bigger picture than we had scope for.’ (FG.16B)*

Working with the ‘bigger picture’ is very difficult and takes some trust and time which is not possible in the assessment framework as it stands. It is a much bigger piece of work.

The psychologist described an emotional reaction in herself to the family’s history:

> *Psychologist: ‘I have a salient memory of something she said in the interview. It was just so painful to consider this horrific experience she’d had, as a mother, trying to… this is the only child she could have, there was so much sadness in this.’ (FG.B15)*

On the other end of the spectrum we can see something more emotionally defended and focused on the functional remit of the assessment which seemed to be how the psychiatrist managed it in this moment:

*Psychiatrist: 'We've done our assessment which is what was expected of us but were not giving a solution. That's in another service and that always feels like an uncomfortable thing to do…'(FG.B22)*

Furthermore, the psychotherapist seems to be in touch with the pain but manages this by keeping in mind that the service will offer another appointment at some point down the line:

*Psychotherapist: 'We didn't have the time to even sympathise a great deal with their experience, you know mum was close to tears, said she tries so hard, the step-father said sometimes they feel like giving up, so that was hard to leave it there, but you know we haven't finished the task so it didn't feel like we were saying 'there you are, closed door' it didn't feel quite so bad.'(FG.B27)*

The underlying difficulties couldn't be addressed by the clinicians with the parents perhaps because of the time constraints as the psychotherapist points out, service limitations as stated by the psychiatrist but from the psychologist's reaction maybe also because there was so much pain to unpack and it was too overwhelming.

The team talks together about the plan to feedback the assessment findings more fully.

*'Psychiatrist: was there an agreed plan going ahead?'*

*Pause…*

*Psychotherapist: 'Were we clear about that? I don't think… yeah, I'm not sure if even in our own minds we had a plan for what we were going to do.'(FG.31B)*

The discomfort of the situation is relieved at the thought that there will be a follow up, but it has also affected their ability to plan and put it in place.

The psychotherapist speaks frankly about the conflict between wanting to help this family and the understandable relief at them being referred on:

> *Psychotherapist: 'I think there is probably some relief (at not keeping the case) as well because the problems are quite severe and being able to make an impact on that is going to be a very demanding piece of work.' (FG.B38)*

This extract shows the extent to which this family provoke a sense of foreboding in the clinicians. The psychotherapist understands the strength of the persecution felt at the thought of attachment disorder being diagnosed as well as the defensive mechanisms that are likely to come up against it.

When talking about extending the time allowance for the clinic or running it over two separate sessions, the psychiatrist recalled doing in-person work with colleagues and because the assessment was in her room, the others would leave but she would be left:

> *Psychiatrist: 'It was very difficult to kick people out, so that was pretty tough…then you have this crying baby that you don't know what to do with.'(FG.B42)*

Her words are very evocative. The idea of kicking someone out is rough and perhaps even cruel. The trauma of the family presents as a conflict in the psychiatrist who is able, to some extent, to keep the functional framework of the assessment in mind. However, this is less possible when other members of the team, perhaps those who are more likely to hold the emotional impact of the trauma, have left.

Trauma affects the clinicians in different ways, and each holds a function for the group. In this case the psychologist is affected emotionally, feels the shock and pain of the trauma. The psychotherapist recognises the trauma more objectively and assures themselves that the family will not have the door closed on them yet. Finally, the psychiatrist is able to be much more matter of fact about the limitations of the service pathway using the resources available to dissipate the more difficult feelings. However, they do let us know that when the other team members leave and they are the only one left, the emotional responsive is more polarised and difficult. This team makes difficult and unsettling decisions in response to a complex and emotional presentation. The way the team functions is affected by how the case and the situation makes them feel.

### 3.3.3 The need for time in processing conflict and coming to a conclusion

This theme examines the idea of how much time might be needed to process difference in opinion whether it might be between parents and clinician or between clinicians.  This relates to previous themes in terms of the need for time to understand the impact of parental trauma and to build epistemic trust, but it also highlights elements of the group process that may affect the assessment.

There is a moment between the psychiatrist and the psychotherapist when they seem to be thinking about whether they might have found more time useful or if it was enough:

*Psychiatrist: ‘In a way that’s what stands out for me for this family is the lack of insight in the relationship issues that they have.’*

*Psychotherapist: ‘I’m not sure whether if we'd had longer, we might have found more insight, actually.’*

*Psychiatrist: ‘No not at all. I completely agree with you. We had enough time to observe… actually even the school observation is superfluous, I mean we already know everything…’(FG.B9)*

It's quite hard to tell whether they are agreeing or not. The wording of the psychotherapist's sentence can be read in two ways, both that they didn't think that anything further would be found, and conversely, that given more time, more would have been found. The tone suggests it was meant that more may have been found with more time. Later in the interview, this point of view was confirmed. At this point, other members of the focus group were able to hear this point of view and take it into consideration, when previously, it seems that the differing opinion was unconsciously felt to be too threatening or undermining of the outcome to be heard. However, at this point the conversation continues without this disparity being acknowledged. It is possible that the emotional complexity and lack of time mean that disagreements are hard to acknowledge.

Later the psychotherapist clarifies with some questioning from the psychologist as to what she meant:

*Psychotherapist: 'If we'd more time then I think probably we could have explored and found that there was more insight into his behaviour.' (FG.B13)*

There is still no acknowledgement of the differing opinions. Further on there is another assumption made about an agreement and again it is not discussed, confirmed or denied.

*Psychiatrist: 'Well I have worked with [Psychotherapist] for a long time, although I don't have the eye contact any more, I can almost guess what they are thinking, more or less.'(FG.B18)*

There is perhaps a risk that with more time there comes a risk of more of a link with the parents, the beginning of some work that is then hard to stop both for the clinicians and for the parents, as well as then to experience a handing over to another team.

The psychotherapist responds to a question about the ideal set up of the assessment:

*Psychotherapist: ‘I think an individual session with mum’.(FG.B17)*

Perhaps it is not just time, but also the group set-up that makes it harder to address sensitive issues.

They also speak about the feeling that what is usually offered is not enough:

*Psychotherapist: ‘we see the emotional impact of the diagnosis and we don’t have the time there and then to see it through and that often feels… erm.. inadequate.’(FG.B26)*

The discomfort of not giving enough sits uncomfortably but hasn’t changed the assessment process.

*Psychiatrist: ‘I think looking back and talking to you, maybe it was a bit disingenuous not to mention what we already have discussed. Because we did discuss it but we didn’t name it…the times we have, its backfired.’*
*Psychotherapist: ‘It’s very difficult when you find… er… well there can be a lot to be said.’(FG.41B)*

The idea of changing and extending the process is proposed:

*Psychologist: ‘Do we have to give feedback on the day, could we not say when we write it up, we will then offer you a time to discuss…’*

*Psychotherapist: ‘I think that’s difficult. In some ways its sound like a good idea but actually they want to go away with something, they don’t want to leave with* *uncertainty, I think you have to give some feedback on the day.' [All talk at once] (FG.B43)*

A change provokes a flurry of thinking and talking. The idea of too much time (waiting for an outcome) is considered, but perhaps there is something about holding the case longer is an issue too.

In this theme, there seems to remain a question over what it would mean to have more time to explore avenues of uncertainty in the group and some ambivalence about uncovering disagreement. It can be seen that there are very mixed feelings about changing the service, although the need is seen, the task is overwhelming.

### Data beyond words: The data of countertransference:

Whilst conducting interviews, similarities within the interviews became evident. These, at times went beyond the words that were being said and subsequently transcribed. With each of the participants the setting up and connecting remotely to conduct the interview was interrupted or disturbed in some way. At this point we were 6 months or so into the Covid pandemic – connecting via Zoom was not a new trend. It therefore seemed unlikely that this would be down to a common grappling with a brand-new technology. With the first interview, it was attributed to 'one of those things'. However, within the context of the interview it seemed that it might hold meaning for the individual participant. As the second, third and further interviews were conducted, I felt irritation, but then I was astounded at the repetition of these disruptions. This one commonality serves as a helpful way of beginning to describe the landscape of the data. Looking across the panorama of data it can be seen, a theme which is made up of the repetition of forgetting, being confused, using the wrong link, expecting a different way of connection, but also of my initial and developing countertransference towards each participant.

**Participant one:**

P1 is the father of a young adolescent boy. His was the longest of all the interviews running just past the 1hour limit that was proposed at the start. He spent the majority of the hour talking about his child's history leading to the most recent contact with the CAMHS assessment team. He began with a small lie that his computer had had to do updates to explain his lateness and then almost immediately conceded that he had just forgotten about the appointment until I had called. At first, I found him arrogant and unlikeable, wanting and expecting too much. I had of course briefed my participants that this was a study contribution to a professional doctorate qualification. He mentioned his own PhD and used technical research terminology. It seemed as if there was some attempt at sizing me up. I was aware of wondering who I was to him. A student or professional? A clinician or researcher? Did I need him or did he need me? Was I with him or against him? All these positions felt like a dichotomy and yet with it could be argued that I was each and every one of these, each role coming to the fore at different moments. We learn in the clinical study of becoming a psychoanalytic psychotherapist that the transference is a way of 'drawing us [the analyst] into their [the patient's] defence systems (Joseph 1978, p223). As therapists, we use this drawing into a position or role to learn more about the defence systems and the reason for it. As a psychotherapist conducting research, I use my understanding not in a therapeutic way as such but to inform my understanding of what a participant tells me not just with their words but with how they position themselves and me in relation to them.

As I listened to the interview again in the transcription process, the trauma of P1's experience of his son's difficulties gradually came more to life, his arrogance and defensive denigrating attitude lessened. I began to understand the irritation I had felt towards him I began to understand as a projection of the trauma of his experiences, of a feeling of helplessness and incompetency. My view of him and subsequently my understanding of his communication changed considerably throughout the process of the data analysis.

**Participant 2**

P2 is the mother of an adolescent girl. She was slightly panicked by being a bit late and then grappling with the technology. She was curious about the research and whether it would be anonymised. She had the second longest interview, a couple of minutes short of the one hour proposed. She too spent a long time talking about the journey that led her to assessment – the first question. The focus was more in the recent past as opposed to the early history, but she did cover her daughter's lifespan to some extent from infancy to the present. She was the only participant who was British and at home in the National Health Service, but also the only participant who is black. She was curious and reflective to my follow up comments which I think made me make more comments edging towards an interpretive or exploratory nature. With P2 there was also incidences of her mentioning her professional status. She presented two quite different sides – one,

the professional stance, talking as if she were in the referrer or assessment team, and the other being a mum who is really concerned for her daughter and needing some framework to explain what was happening and how to make things better. I found myself being quite aware of these swings in her position during the interview and wondering how it changed how she saw me. P2 made some very critical comments about the assessment, some being quite personal towards an individual clinician. These rather hate filled moments were quite intense and alive despite her changing her relationship with and opinion of this clinician later on. This sparked something more defensive in me which I noticed rather strongly and although I don’t think it effected the line of the interview, in this moment it made the participant less likeable and I wondered if in other circumstances it may have effected a therapeutic relationship with her. P2 pondered on her reasons for agreeing to be interviewed as well as wondering if she would be heard by anyone and if what she said would make any difference. Together we made a link between her assessment experience and an earlier experience in her life, that made me wish for her to have some more explorative work available to her. I wondered how much was this my wish, my enjoyment for this work and how much was I uncovering her unconscious wish to explore something that was currently being presented as a need for help for her daughter.

### Participant 3

P3 is the mother of a latency aged boy. She is white but not British born, and although she has very good English, she struggles with expressing herself and understanding me at times. She comments on the difficulty of navigating the diagnostic system and the associated educational system for someone who has not grown up here. She misremembered the plan made in setting up the interview and was expecting a phone call. There were then some technical difficulties making contact and getting into zoom. The interview was delayed by around half an hour. Given that the previous two interviews were also delayed I was thankful that I did not have an appointment lined up straight after this interview and made a note to allow for a similar time scale for my subsequent interviews. She had a clipped, brusque tone and appeared flustered and apologetic when I asked if she had the information and consent forms. I felt more on edge with her to begin with, wondering if she would align me with the clinicians that I began to assume that she was not happy with. She told me proudly about her busy job and quickly let me know that the children were with their father with whom she had separated from. She gave the impression that she was selflessly fitting me into her very pressured schedule, but along with the apologetic tone, gave the sense that she was accustomed to working extremely hard always prioritising someone else's needs. She had the shortest interview at around 40minutes and was the least interested in thinking about the whys and hows. I felt that there were things that she would not want to talk about and it could be felt as assaultive to try. She wanted some help for her son and had seemed to have gone past the reasoning stage and was simply doing and saying whatever might make this happen. She often laughed at moments that seemed to hold the most emotional pain and distress. This had a somewhat hysterical feel to it. I felt that this was a desperate and fragile woman at a loss as to how to get the right help for her child.

**Participant 4**

P4 is a mother of two older adolescent boy twins. She is white and also not British. The assessment was in relation to just one of her children, although the other also had additional neurodevelopmental needs. She too forgot about the appointment and then tried to use the video link that the clinic uses rather than the zoom link I had sent her. We were on the phone for about 10 minutes trying to work out which link to use or whether to stay on the phone. She was quite annoyed and made comments to let me know how many demands she had on her. When she finally realised that she had received an email from me and that it was she that had missed it, she was very apologetic. The switch from angry to apologetic was stark and gave me the impression of someone quite overwhelmed and emotionally fragile. I found myself feeling like I needed to treat her very carefully. Being not British born and having grown up in a different country and culture to her sons seemed significant to her as well as the difficulty in navigating systems that were not familiar to her. She let me know that she worked in research but did not use, comment on or question my academic programme or work. She did not use any technical language. She sighed, paused and spoke slowly at times. She had forgotten specific details about the assessment, she couldn’t remember the month it happened or the alternative diagnosis that was given. She didn’t remember any of the names of the clinicians that assessed her son. Sometimes this felt as if she was placing no importance on the assessment which I found frustrating. As I analysed her data, I wondered if this had been due to her experience since the assessment. The lack of follow up had devalued anything that she may have gained from the assessment. Or perhaps the clinicians have also sensed her apathy and had responded equally. At times when she seemed lost and helpless in the system, not know what would come next or how to move forward I felt more sympathy. I wondered how she had been in the assessment and what this may have evoked in the clinicians. However, in moments she had more clearly an ideal in her mind of what she would like – a ‘supernanny’ type method of help. Someone dedicated to the specific family situation who gave hand over hand type of instruction. Her mind was clearer when she had someone with a clear mind in her thoughts. Doubt with this participant was very hard to tolerate.

These personal reflections informed by my psychoanalytic training, effected my understanding, interpretation and analysis of each interview.

# Chapter 4

# Discussion

This research project aimed at understanding the experiences of parents when going through a complex neurodevelopmental assessment with their child. This was through examining both their reported accounts, but also through the assessing clinicians experiences of them with particular focus on their possible counter-transferential responses which may be further informative about the parents' experience. Countertransference responses are understood to reflect the unconscious, defended motivations and communications usually of the patient, but in this case of the parent participant. The researcher used their own countertransference responses to the parent participants as a way of helping to link together these elements of data.

The main research question was: 'Can we better understand the experience and outcome of complex neurodevelopmental assessment by considering the perspectives of both parents and clinicians? '. As described in the introduction, this research question was developed with a number of other sub-questions in mind such as 'what drives parents to seek assessment?', 'what did parents experience in the assessment and why?', 'what did parents make of the outcome of the assessment?' and 'do the clinicians counter-transferential responses tell us something more about what parents experience when they use this particular service?' I return to these questions in this chapter, relating them to the findings while discussing them with the relevant literature. Four parents of children who went through the complex neurodevelopmental assessment clinic of an inner-city hospital, were interviewed with a semi structured interview based on FANI methodology. Three complex neurodevelopmental assessment clinicians - a psychiatrist, a child and adolescent psychotherapist and a clinical psychologist, as well as two observing psychology students took part in a focus group. All the data were analysed IPA.

The analysis of the parents' interviews retrieved the following three recurrent superordinate themes:

1. Parental trauma and the role in the child's difficulties
2. Difficulty, uncertainty and the development of epistemic trust
3. A persecuted state of mind: how assessment effects parental sense of self and clinician

The analysis of the clinical staff focus group also captured three superordinate themes as listed below:

1. The clinicians experience of knowledge and power
2. The presence and management of parental trauma in the assessment framework
3. The need for time in processing conflict in coming to an agreement

Overall, the results indicated that parents were universally struggling with traumatic experience. This came in a variety of forms, event trauma, relational trauma, a sense of anxiety and a lack of efficacy with their child, experience of severe behavioural difficulties, lack of familial support, being away from their home culture and familiar health, education and parenting practices. Moreover, the results showed how blame was a central feature within both parents' and clinicians' experiences of the assessment: in the parents this was expressed by both at times blaming others for things going wrong with their child, feeling blamed, and even wondering if they themselves were to blame for the difficulties. This was one of the most pertinent themes for the clinicians too. With the sense that parents were defensive against gaining a better understanding of their role in the child's difficulties, the clinicians were very uncomfortable with addressing this and felt compelled to rather stick to the narrow task of ruling out a diagnosis, rather than addressing the underlying issue. This strong counter-transference of not being able to address relational issues with the parents helped illuminate the experiences of the parents, particularly when they felt mistrust or criticism from the clinicians. There is a sort of psychic 'no-man's land' which leaves mistrust, a lack of sense of resolution and a question over how to continue with assessment or access help. The clinicians felt dissatisfied with this, but there were both group dynamics such as no allocated person to set up a follow up meeting as well as institutional dynamics for example the chronic under funding of the service that served as defences against the painful counter-transference experiences during the assessment and prevented them following up with more applicable observations and knowledge of their understanding of the child after the assessment. Finally, the results show how the short time limit on the assessment was in both the parents' and the clinician's minds. Although lots of time was not always necessary for building epistemic trust, it did seem an important factor for beginning to address some of the relational aspects underlying the child's behavioural difficulties.

In the following sections, each superordinate theme is discussed in relation to the relevant literature. The first superordinate theme from the parents and the second superordinate theme from the staff focus group are looked at together as they are describing something very similar from the two different perspectives. It was felt that this would be both appropriate and helpful in the work of discussing and evaluating the findings of this project.

### The triple hermeneutic

Previously, the double hermeneutic as traditionally acknowledged in IPA was discussed. However, with further experience and consideration, a triple hermeneutic or hermeneutic circle seems more appropriate. This is also in line with the psychoanalytic use of transference and countertransference. As Heinmann (1950) describes, countertransference is one of the most important tools '*it is an instrument of research into the patient's unconscious'* (p81). However, she also acknowledges that how the patient feels about the analyst as well as how the analyst feels about and reacts to the patient does not always belong to the transference. This same issue presents as a challenge in this research as well as in the clinical process.

In this section there is an attempt to draw together the three parts of the data including where the unconscious processes of transference and countertransference can be understood and used as Heinmann suggests as a tool of research to better understand what is happening between people. This means using a layering and an oscillation of understanding that helps us reach a deeper level and a bigger relational picture.

Taking note of how the participants affected the researcher shed light on how the family focused on by the clinicians affected them. This gave a further level on which to understand what the participants said about their experiences. Of course, this degree of interpretation of what is said and what might be understood using the researcher's understanding of the psychoanalytic theory of defensive processes brings a tension in terms of what might be considered valid evidence. Fonagy, in Midgely et al, 2009, discusses the difficulties of finding 'truth' through understanding using a psychoanalytic philosophy. However, he also notes '*communication, whether in writing or clinical discourse, can be judged by its impact.*' (p20) The interviews conducted, including the focus group, were incredible powerful and were felt to be moving to the participants as well as the researcher. Beyond this emotional quality, they were also felt to be productive at times. That is, that the participants were able to make connections between past and present that seemed to be developmentally progressive. Skogstad in Stamenova and Hinshelwood (2019) talks about how unconscious defence mechanisms can become more evident when psychoanalytic observation occurs. He notes that conscious intention or behaviour can be quite in contrast to its effect, and it can be possible to conclude an unconscious defence has somewhat sabotaged the conscious intention in order to deal with difficult feelings. This process is not always pathological, and indeed can be observed in daily life. However, when in the clinical situation recognising this process can be helpful to initiate progress in conflicted states. This was the sense in the interviews, although of course with some limited or unknown impact given the limitations of the study itself.

In the final sections of the discussion, the potential clinical implications will be discussed, as well as the limitations of this research and indication for future research.

## 1. 'Parental trauma and its role in the child's difficulties' and 'The presence and management of parental trauma in the assessment framework'. (Parents' theme 1 and focus group theme 2)

One of the most striking things that arose from these interviews was a real sense of trauma within each of the parent's stories. This seemed to be mirrored by how complex and difficult it was to understand, attend to and try to extrapolate what might be understood as a diagnosable neurodevelopmental condition. Anne Alvarez (1992) spoke about the inextricable nature of the parents' and child's experience, like a double helix, each intertwined with the other. However, I might go further to say that in the cases in this study, it is something more akin to a French braid, strands coming in from different directions, at different times, intertwining into a really quite complex picture. There are mentions of trauma within some participants childhoods, in their families of origin; there are two incidents of parental couple separation, three of the parents being no longer in their home country, without extended family nearby, they are navigating unfamiliar health and education systems and parenting outside of the culture they grew up in; there is a brain bleed, a head injury, a damaged vaccination, self-harming behaviour; and the trauma of feeling as if there is something wrong and not knowing what it is or how to manage it. Parents used their past experiences, whether these were in their own childhood or earlier in their child's childhood to contribute to their reasoning around why they wanted this assessment and what they wanted from it. It wasn't always directly stated, but their recollections helped bring some cumulative evidence within the interview. For example, P1 and P2 reflecting on distressing experiences with the health of close relatives in their own childhoods when they were relatively helpless. A sense of injustice and statement of the steps they have taken to remedy issues for their own child were key in their interviews and narratives. With P3 and P4 there is more of a sense that their child had had some external failure in their earlier childhood and the assessment and diagnosis had a focus here. However, all the participants, at one time or another, spoke of anxiety about a personal failure or deficit that may explain or contribute to the presenting problems of their child. Working out where the trauma lay and what if any effect this had had on the child's presenting problems seems to be both the work of the parents and the clinicians. However, this is far for being a straightforward task, as defences from both parties complicate and inhibit the investigation.

Main (1957) observed that nurses gave patients a sedative when they themselves could no longer bear the disturbance, rather than when the disturbance of the patient was increasing. Similarly, to the nurse who must take care of the patient, the parents must find a way to look after their child. Main points out that the focus of what was felt to need to change was on the patient, rather than on the nurses' ability to understand and help or to have some support for themselves. When thinking about parental trauma and the reaching out for help, it seems that the state of mind of the parent must be considered in how they experience their child, what it evokes for them, how they cope with the difficulties and whether, as Maté (1999) suggests, the difficulties are a product of relational disturbance.  Fraiberg et al (1980) and Widener (1998) underline the importance of understanding the role of the parents' experience in the child's presentation. It is only in this way that the most appropriate form of intervention may be identified. Fraiberg et al understand the child's behaviour and/or symptoms to belong somewhat to the parents from their childhood, repeating in their parenting.

All of the parents have moments when they consider the question 'why is my child like this?', and three of the four considered that it may not be a neurodevelopmental condition after all. Of course, the clinician's job is to both think about whether or not the child presents with traits that could be in line with a neurodevelopmental diagnosis, but also, in this assessment, what else the symptoms might indicate. During the research interview each of the parents took the opportunity to tell their stories and process something of their experiences. Some used the maximum amount of time available in the interview and both seemed to benefit from this experience. Others were shorter, less in-depth interviews being less descriptive and comprehensive in their stories and perhaps this could be due to those parents' first language not being English. In the clinicians' focus group, it was seen that the clinicians experienced a sense that the parents were too traumatised to have a discussion about how their relationship with the child may have contributed to the presenting problems. This experience seems to have come from an unconscious communication from the parents that told the clinicians 'don't go there'. The clinicians received this message and felt a deep discomfort and made decisions that led to a lack of follow up and a delay in report writing. This lack of follow up was experienced by some of the parents interviewed, so it might be considered that the clinicians they met with were under similar unconscious processes. The difficulty addressing relational trauma, followed by a defensive avoidance may have bolstered the narrative that some of the parents described around not being understood, or the clinicians not really being interested. In turn, this once again locates the 'problem' outside of the relational structures.

Klein (1946) described the process of splitting and projection as a way of managing unbearable experiences. While she notes that this is part of an ordinary development in early infancy when the ego is not yet integrated, namely the paranoid-schizoid position, she also reminds us that this position can be revisited later on in life when anxiety is particularly high. When thinking about the difficult process of assessment and uncertainty and when reflecting on stressful or traumatic moments in life, splitting and projection may once again be employed in order to retain a sense of holding oneself together, albeit in a compromised state. These were seen clearly in the complex narrative of some of the participants, like P1, where traumatic events were recounted, one blow after the other, indicating clear examples of effective projection.

In these moments I found myself feeling emotionally affected, as if what this particular participant was reporting was happening in the moment while he retained a stance of a storyteller and did not seem emotionally affected. However, I could feel the connection between father and son and the excruciating task of them trying to negotiate when to act and when to resist.

P1's history includes a sister possibly not too far away from his son's age experiencing a lifetime of suffering at the hands of a serious mental health condition. The effects of all these events, past and present, still need a lot of processing and seem to affect the present-day assessment and parenting of the child. We can start to see how projection can affect clinicians, or researcher, in a temporary way. This allows us to understand the impact on children when their experience of projection from their parents is likely to be in a far more sustained way and therefore, with deeper potential developmental implications (Rhode, 2018)

The results show how a sense of trauma remains projected and not contained. Within the context of the assessment and the interview, this could have been partly due to the time limitations, but perhaps also to the fact that it was by necessity, done remotely by video conference, although this was hardly mentioned by the participants. The assessment restrictions seemed to reflect the restricted and constricted emotional experience of the participants. Indeed, at various points participants seemed almost anesthetised to the reported traumatic event, leaving the interviewer with feelings of shock, fear or upset.

The need to project the emotional experience tells us that it is overwhelming. Returning to the question of ‘what drives parents to seek assessment?’, the results seem to indicate that there is a wish to make sense of complex behaviours and overwhelming feelings in a structured and organised way, such that it can be in the case of assessment with a diagnosis. At their core, diagnoses can be pinned down to a list of traits or symptoms, a number of which must be met in order to reach the threshold for diagnosis. This is clearly a simplified way of viewing a diagnosis, but it seems as if parents may find the idea of something simple and straightforward a huge relief in the face of something overwhelmingly complex and disturbing. Lawson et al (2013) described elements of parents trying to regain some sense of control in relation to their child’s diagnosis. This potentially could be taken further, to think about parents taking control of their own lives, especially when they had experienced trauma, projecting unbearable parts of themselves into the child or into the clinicians, as the results of this study suggest, when participants reported disturbing or painful events without showing or describing the emotional impact on them and attributing the feelings, which might have originated in them, to the children. For example, when P2 spoke about her mother moving abroad while she was coping as a single mother, she attributed the difficult feelings to her daughter without owning any herself. It seems possible that these feelings originated in herself.

This largely concurs with Pozzi’s (2000) thought that ‘failure in the containing function of the primary figure’ can contribute to ADHD-like presentation in children. Perry et al (1995) demonstrate that children are neurologically more adaptive than adults.  Children will therefore adapt to states of trauma which could include emotionally uncontained adult states. This suggests that children’s neurodevelopmental states may speak to both their parents’ trauma and of how as parents, they were able to relate to their children. Singletary (2015)'s integrative model of autism illustrates again the adaptive and maladaptive routes that children's innate biological inheritance can take in response to their environments and how this may be understood in clinical work, but also in potentially adjusting environments for better outcomes. This seems to value a focus on aetiology as well as the meaning of behaviour, for the most optimal outcomes.

Reflecting on the clinicians' theme of 'The presence and management of parental trauma in the assessment framework', we can see the effect of the parents' trauma on these highly skilled and experienced professionals. Speaking about relational difficulties in families is a key part of their roles, but the intense pain of the parents when attempting to look at their own emotional experiences inhibits the clinicians somewhat and affects the assessment process. Zachary, in Armstrong and Rustin (2015), found that staff responses can 'mirror' aspects of patients' presentation. This is in line with what the current research seems to indicate that when the parents have such a strong emotional response of turning away from linking their trauma with the behaviour of the child, or they return to a paranoid, persecuted state, the clinicians may also be less able to address what they see in the parent/child relationship and how it connects to the symptoms that have brought them for a complex neurodevelopmental assessment.  The parents in the current research, indeed, were avoiding the link between their traumatic pasts and the current difficulties which were being located in their child. When thinking about the underlying question around what parents experienced and why, as well as what they felt about the outcome, we can understand that when the assessment process disturbed their defences against their own traumatic experience they are propelled into a more persecuted state of mind. This will be discussed below in parents' theme three.

### 2. Living with uncertainty and the development of epistemic trust (Parents' theme 2)

Remarkably, in each of the interviews, there were difficulties or delays in participant connecting with the researcher. These took the form of forgotten times, a misunderstanding about the method of remote communication, difficulties finding the link etc. These minutes of uncertainty and waiting offered an opportunity for the researcher to experience some of the range of feelings provoked by uncertainty. The notes made at the time of the interview (as recorded above) reflect these and seem relevant when thinking about the projection of unbearable experiences. The fact that this was a common feature in all four interviews suggests that there might be a need for their difficult experience of waiting and not knowing and for their ambivalent relationship with the clinic to be contained.

Similarly, to Carlsson et al's (2016) study, each of the participants wished to have some further clarity about their child's behavioural and/or emotional difficulties. They found relief in a diagnosis but also each seem to have a wish for someone to be alongside them in their complex journeys of getting to understand their situation and what help they might need. We saw that the clinicians were tentative to address areas that in their countertransference were sensed to be 'no-go areas' The pressure to placate or not to upset parents seems to have the effect of it being difficult to be with them in an unsettled or uncertain place. All found it very hard to live with the continued uncertainty. This did not link just to diagnosis but to treatment, faith in the assessors, support for themselves and the future of the child and their wellbeing. Peter (2021) described the difficult position of child and adolescent psychotherapists when trying to work with both a biomedical framework - within which medication would be considered - in mind as well as their psychoanalytic understanding. In her study she writes that child and adolescent psychotherapists: *‘Participants rarely pointed out any conflict between seeing symptoms as meaningful communications, compared to the use of medication to eradicate them.’* (p46). She describes how the biomedical discourse can create a polarising effect with a ‘parent-blame’ discourse at the opposite end from the biomedical. This can align psychotherapeutic, meaning making treatment with something rather blaming and persecuting.

The results show how, in some participants the need for clarity and certainty prevailed, while others became more able to tolerate ambivalence and uncertainty. The latter reported an experience of the clinicians as containing either during the assessment or after, once some treatment was offered. This containing presence is what Bion (1963) described as container/contained. In that moment, the difficulty and the uncertainty felt by the parents about the future was felt to be manageable because the emotional experience was felt by the clinicians and put into words for them, or because the clinicians join the parents in a state of not knowing. This was a moment of helpful containment. They seem to be embarking on a journey which Bion (1962) might describe as the process of learning from experience or ‘K’ – tolerating not quite knowing but being open to finding out more. These findings concur with Twomy and Shelvin’s (2017) findings of needing to feel understood to protect against a ‘legacy of mistrust’.

However, moving past the diagnostic question, uncertainty is experienced again when looking at ongoing care and treatment. As Buzanko (2018) and Chao et al (2018) emphasised, living with such uncertainty was very stressful. It seems likely that this time of not knowing and the desperate search for some meaning, may prompt parents to consider their own role in the child’s difficulties. The presence or absence of epistemic trust may potentially contribute to the sense of this assessment being either particularly difficult, or helpful. There seems to be a wish in all of the participants to have a meaningful link with a clinician with whom they can grapple with the problems they face. The difficulty presented here is described well in the first theme from the staff focus group which will be discussed in the following section.

### 3. The clinicians’ experience of knowledge and power (Focus group theme 1)

The counter-transferential experience of the staff was particularly prominent and important for this theme. There was a strong feeling that there was so much that could not be addressed within the assessment. Staff conveyed a sense that what they knew that was underlying the difficulties of the child must not be mentioned or addressed. Twice the psychiatrist uses the metaphor of having to ‘sugar-coat a bitter pill’ demonstrating that something had to remain untasted.

The psychotherapist grapples with having the knowledge that this child and their parents are struggling with an attachment disorder. This is something that as a clinician they would be perfectly able to work with, but the team is only commissioned to assess for neurodevelopmental disorder and work with those who meet the threshold for a diagnosis. It is also a service that identifies the child as the patient. There is a rather grey area when the parent comes to the fore as someone in need of help. In child psychotherapy, help is often offered for the parent as a parent, but of course there is no clear line when this stops and more individual work begins. Parent work requires consent, and sensing a ‘no-go area’ could certainly contraindicate approaching this. They, therefore, sit with the conflict of what is wanted and what is needed, but also more internally, a terrible feeling of having to reject a family and refer to another service.

The way the clinicians speak about the experience of the assessment, demonstrates how powerful counter-transferential processes are taking place; for instance they speak about feeling ‘pushed away’ or ‘left holding the baby’. While it becomes clear how it’s unbearable for the parents to face the truth of their child’s difficulties, it is also unbearable for the clinicians to voice it. The feeling of being left holding the baby shows a sense of the emotional impact that the clinicians are defending against. There is something of a paralysed countertransference. This I think has come from the powerful unspoken communication from the parents that what they fear the most must not be mentioned. It also helps us understand the deep fear that they may have around whether anything can be changed. In three of the four interviews, moments of anger in the parents were strongly felt. It is conceivable that anger may have been communicated in a less up front way towards the clinicians again giving them the message that they must not address certain areas. Given the lack of consent to approach more adult based needs and the remit of the clinic being diagnostic, it is understandable why the clinicians might opt to not take the route of addressing relational difficulties.

The results show other examples of defending against the intensely difficult conflicts that are presented as the assessment unfolds. The team begin to think about how little the team is funded for these assessments. There is a thought of the ‘organisational needs’ in conflict with the patient needs. It is felt that spending more time or dedicating more resources to the families that don’t meet the service pathway post assessment cannot happen because of this underfunding. There is a counter argument that this might not matter. This realisation seems to uncover something less conscious – a wish not to work with these more complicated and defended families. Indeed, it is revealed that although there was a plan to hold a follow-up meeting with this family, actually no one had arranged it or taken ownership of the task. The psychotherapist then speaks about it being somewhat of a relief to be able to refer this family on. It is possible that the parents' anxiety about facing relational issues were transferred into the clinicians who with their time limits and waiting list pressures took it as an agreement not to go into that area of work. This results in dissatisfaction all round. Each parent participant felt dissatisfied with the assessment experience at one point or another and this demonstrates how it might have been located via the transference situation into the clinicians. It could be considered that to face the relational issues with the acknowledgement that it is very hard and painful may be difficult, even unwanted by the parents, but may also be somewhat more conclusive and satisfying in the longer term.

As Anzieu-Premmereur in Bronstein and O'Shaughnessy (2019) tells us, there are challenges when engaging with the parents of a child with great difficulties. The inextricable nature of the parent/child relationship means that, as Rustin (in Lanyado and Horne, 2009) suggested, and as the present results indicate, the difficulties of one effect the other. Where the problems originates and where work needs to be focused are difficult questions. There is risk of the parent-child relationship developing in a way that causes problems. This may be because of trauma in the parent's past combined with an inherent biological problem in the child as well as any number of other variables. The 'competition, jealousy and envy' that Rustin speaks of may occur when the defensive mechanism of projecting out one's difficulties is disrupted during such an assessment. This may shed light on why the clinicians in the focus group felt so uncomfortable with the task and the thought of working more with this family. There seems to be a sense of danger or threat in addressing the underlying difficulties. This feeling could originate in the parents as a threat to the defence mechanism that has perhaps allowed them to get through their traumas, and is felt in the counter transference of the clinicians when they are faced with knowledge that would need substantial investment to be therapeutically helpful to the family.

As Chuard (2021) describes, groups can move, even very temporarily, into 'basic assumption' (Bion, 1961) modes of work. This is a more instinctive mode of working and doesn't hold up against scrutiny. There is something of a 'flight' type of group as each does not take on the task of setting-up a review with the parents. There are influences on the group of clinicians from the family of the child they are assessing, the institution that holds the budgets and that which defines the assessment pathway. There are perhaps also moments when a sort of 'dependency' mode is reached when there is reliance on an institution to hold responsibility for the way in which the assessment pans out with the purpose of managing the overwhelming difficulties and pain of a very complicated case.

## 4. A persecuted state of mind: how assessment affects parental sense of self in relation to the clinician

## (Parents' theme 3).

*The lady doth protest too much, methinks. (Hamlet, Shakespeare, 1599)*

The parent's sense of identity emerged strongly as a theme. Again, the question of why parents might seek assessment and then perhaps be disappointed at a lack of diagnosis arises.  There were many moments when parents became very defensive as suggested in the quotation above from Shakespeare’s Hamlet. When there were explorations into the child’s family history, or when the clinicians disagreed with something the parents did or said or even just with what the parents expected, there is a strong persecuted reaction. This causes a chain reaction, at times for the parents to question themselves, and at other times to question the skill or intention of the clinicians. As we saw in the focus group this persecuted reaction can have a paralysing affect on clinicians. All the participants seemed to experience a sort of crisis of confidence, even if momentary, in relation to what they experienced in this assessment. It also affected the group process of the clinicians which will be discussed further below, but we might surmise that despite being highly qualified and experienced professionals, the clinicians may also doubt or question themselves when there is a strong conflict of opinion. This in turn may affect the confidence that the parents had in the clinicians’ decision and a negative cycle is seen to be at work.

In each of the participants’ interviews, their professional identity was mentioned. Some revisited it several times almost to the point where it felt that they were competitively setting themselves up against the researcher or clinicians. At times they emphasised the normality of their own childhood, they normalised some of the symptoms, and even criticised the culture that the child was being brought up in compared to their own culture of origin.

There are many points in the interviews when parents considered why their child is the way they are. However, there are moments when they seem to move from a solution-focused position, to thinking about their own part in the difficulties, either as the person who passed on a bad gene, or a defective parent, or as someone who has missed vital symptoms or such like. There is this self-persecution, but there is also persecution felt to come from the clinicians when a diagnosis is resisted against.

As Pozzi (2000) suggested, parents may wish to look towards a more medicalised explanation of their child's difficulties because of the potential for unbearable guilt and to absolve them from responsibility. It may also be that to see one's offspring as unsuccessful in development, may also be to see oneself as unsuccessful. Anzieu-Premmereur in Bronstein and O'Shaughnessy (2019) states the possibility of reawakening of a narcissistic wound. Symington and Grotstein (1993) note how difficult a narcissistic position can be to work with owing to the fact that it may well have developed as a protective defensive measure and so will not quickly be given up.

This was seen in the participants, how much they were defended, and how such defence could come across as arrogance at first. Only thanks to the fine analysis of the interview using the interviewers understanding of transference and unconscious defence, a more vulnerable and sad side of the participants could be seen and understood. The initial experience is hard to tolerate and may contribute to a vicious cycle of turning away from a focus on emotional and relational trauma rather than a medicalisation of a set of symptoms or behaviours. However, again owing to the fine detail nature of IPA, there also seem to be signs of what Klein (1935) may have described as a move towards something more like depressive concern. A more realistic relationship interaction is considered prompting anxiety that stems from some knowledge of their contribution to the child's difficulties. Although this is very painful, it can also be helpful for both child and parent in their development if there is some containing support to face this without it becoming again overwhelming and prompting further defences to be activated.

As Houzel in Tsiantis (2004) remind us, it is with a focus on the meaning of the child's behaviour or communications, rather than on aetiology, that may reduce the persecutory anxiety related to this sort of assessment. The development of epistemic trust thorough the establishment of a containing relationship that may be able to recognise and cope with parent's defences against highly anxiety provoking states of mind seems necessary. It is prudent to recall to mind that these assessments were conducted over Zoom as a necessary adaptation to Covid-19 restrictions. This raises an important question regarding the difficulty of establishing rapport, and even working towards a sense of epistemic trust through, not only a single encounter, but also with the potential impact of it being a remote, screen-based encounter.

All participants spoke of a state when they were left waiting for the next step with information that wasn't fully understood or processed. Three participants were not happy with the initial outcome of the assessment, only one was satisfied, but then returned to a persecuted state when there was little follow up after assessment.

Many of the research papers cited earlier (e.g. Howlin and Moore, 1997, Braiden et al, 2006, Carlsson et al, 2016, Twomy and Shevlin, 2017) made helpful conclusions about what it was in the assessment process that made it feel satisfactory or unsatisfactory to parents. However, the current results suggest that there seems to be some value in thinking about whether this feeling comes from a placatory experience or from engaging in a psychically disruptive experience which although may be disturbing, is also enlightening. That is to say that psychic work is often necessarily painful. The current results seem to direct us, as clinicians, to focus our attention on rather asking how we can help parents bear that painful dissatisfaction.

### 5. The need for time in processing conflict and coming to a conclusion (Focus group theme 3)

This theme describes some of the group process that happens in the clinical team during the focus group interview while reflecting on the group assessment. It marks how the team's thinking develops over time as well as how it is curtailed, perhaps due to a lack of time. It is reflective of moments when parents felt that they were not afforded enough time either in the interview or afterwards to reflect, ask questions and have more detailed feedback. Busy NHS clinics are always time pressed, but there is interest in which cases get time and resources and which do not. This theme seems to concur with Twomy and Shelvin (2017)'s findings that parents felt that professionals' views of parenting were at times oversimplified. It suggests that it was felt that professionals did not understand their particular situation well enough, but also that they were not interested or invested in their care.

Towards the end of the focus group, there is some discussion about whether the assessment and the feedback must be done in the same session or whether the feedback can be delayed allowing for more time both for the clinicians to discuss, but also for the family to process the experience. It is thought that the uncertainty that may be felt as they wait for the assessment conclusions would be too difficult for the parents. It is evident in parents' theme 2 that uncertainty is difficult to cope with, but that minimal, time pressured feedback and an unknown time-frame for follow up perhaps create more uncertainty than it avoids. The reader may recall that the original offer to parents was a single interview with the possibility of a follow up session should the participant want or need it. This second session was neither requested nor offered again during the interview, perhaps again reflecting the interviewer's own ambivalence about opening up more that could be managed in a small time-frame.

There is also some uncertainty in the clinicians over the outcome of the assessment discussed However,  this, as shown in the results, is not easily acknowledged. We know from Menzies-Leith (1960) that when an organisation or its members are threatened to be emotionally overwhelmed, defences can be triggered. As Canham (2002) described, working groups can temporarily shift to ‘gangs’ where individual differences in opinion in members cannot be acknowledged.

As shown in the results, differing opinions are overlooked at points and noticed at others. This highlights the moment-to-moment shift between the group functioning. Similarly, to the parents, there is a sense in the clinicians, that the assessment was too superficial, and that something was missed.

Buzanko (2018) wrote about parents having the sense the clinicians were not always transparent with them. Certainly, there seems to be some evidence for that in the present results. Not having time to address the difficulties that do not come under the institutionally imposed diagnostic pathway, is reminiscent of Menzies Lyth’s (1988) writing on social defences within hospitals. The clinicians find themselves conflicted, knowing intellectually what this family might need, keeping in mind that the family do not meet the narrow criteria for treatment, feeling as if what they have given is rather unsatisfactory and yet, perhaps hardest of all, a sense of relief that they will not be the ones to take on this very difficult and potentially distressing piece of work. The ‘crying baby’, as described before by the psychiatrist, can be passed back.

There seems to be a running theme of blame and responsibility. There is great terror, seemingly stemming back through generations, that something terrible will be wrong and that as parents, they feel overwhelming guilt. Added to this is the fear that this guilt will be corroborated by clinicians somehow triggering a rather devastating collapse and erasing hope for the future of the child and the family. Clinicians bear the weight of this desperate communication, while also navigating their various responsibilities and positions in the inherently hierarchical institution of an NHS hospital.

### **4.1 Limitations**:

Researching this clinic whilst also training and working in the same team has made the element of subjectivity necessary for IPA particularly difficult. At times there may have been acting on me, the pressure of loyalty, a wish to learn from my seniors while also having something to contribute myself. A desire to improve is inherently critical and while this project was supported by the team, and of course contributed to by them, the nature of IPA as well as the FANI method, is to illicit defended elements of communication. That is to illuminate for the purpose of understanding defended motivations which may have become so due to vulnerable aspects of the self.  The analysis and results of the data will have been affected by being so closely attached to the clinic and having this knowledge in mind.

While the interviewer’s first language is English, it was not the first language of all the participants including the clinicians. This may have been a barrier to a deeper connection and fuller interview and therefore affected the meaning making during and after the interview.

Lastly, although qualitative research, and particularly research for the purpose of a small-scale project for a professional doctorate is expected to have a small sample, it is important to acknowledge that the results from four parent participants and one focus group of clinicians are not generalisable. It is a starting point for thinking about experiences of assessment of children, of their parents when it is often the parents that are presenting their child's difficulties and asking for help.

## 4.2 Validity

This study was planned before the Covid-19 pandemic of 2020. It was adapted to cope with the remote working that was necessary at the time. This team was just beginning to adapt their skills to remote assessment. The parents interviewed were experiencing clinicians who were working outside of their normal practice, replicating a sensitive, in-depth assessment over Zoom. This will have affected the assessment experience itself, as well as the ecological validity of the study and the ability to apply it to a returned state of in-person assessment.

### 4.2.1 Methodological validity

By using FANI to develop the interview schedules, as well as the tools of writing 'pen portraits' and careful notes of personal experience during the interviews, alongside a carefully followed IPA methodology, this project is felt to have good methodological validity. Triangulation between the themes constructed from the parents' data and that of the clinicians again suggests that this is the case.

## 4.3 Indication for further research and clinical implications

There is a clear question about how best to help parents who are highly defended against thinking about relational aspects of their child's difficulties and whether a neurodevelopmental diagnosis is a vehicle for accessing and providing substantial therapeutic work within the context of a containing therapeutic alliance. Understanding neurodevelopmental conditions to have a complex, combined aetiology, suggests a need to research into the possible benefits of differentiated diagnosis, and to regularly review the need for a diagnosis, rather than it being considered permanent and life-long. It has become clear that at times, asking for a diagnosis is a parent’s way of reaching out for help, and with this understanding we must strive for assessment and the understanding gleaned from this to be as helpful and containing as possible to enable parents to feel some epistemic trust and to accept further help, within or outside of the service. One way of doing this might be to pre-empt the assessment with a more substantial connection with the referring party. This is often where the idea of assessment is initiated. It could be that exploring non diagnostic pathways and considering the difficulties as forms of meaningful relational communication to be understood would be very important. As Peter (2021) suggested, this sort of challenging work is best done within and between teams. Working with non-diagnostic pathway teams rather than shuttling families between them/us could be helpful and more containing for families.

Further, it seems that there is significant evidence to support the need to address anxiety in parents around their impact on the child. Recognising the anxiety and experience such as the clinicians had, for example the sense that some subjects just couldn’t be addressed, might be more usefully brought into the conversations with parents. This of course would need a greater time allowance and commensurate funding. Although this additional input would be hard work, it may also help heal the dissatisfaction felt by both parties and avoid the void after assessment. As previously described, working more closely with the parent needs explicit or implicit consent and this requires careful navigation around professional responsibilities and remits of the team. I would suggest that families coming for assessment have a named professional with whom they can liaise with. This would have the goal of helping build epistemic trust through a therapeutic relationship and allow for a more personalised service. The assessment must remain as an MDT assessment, but with a named contact for the family.

Finally, the work conducted here with clinicians has shown that there may well be some value in a reflective work discussion group especially when working with families and young people who provoke strong responses in clinical groups. With the online structures of work expanding more vigorously than ever, I would like to see reflective groups for assessing teams which add value to this critical stage of work that is often relatively unsupported as it is generally much shorter term than ‘treatment’ phases of work.

### 4.4 Conclusion

This research and its results deriving from the participants’ experiences and the clinicians’ reactions, including their countertransference responses, provided a better understanding of the increasing complexity of the cases that are referred for neurodevelopmental assessment. There is expanding research on presentations of autism and ADHD. However, as demonstrated in the literature review, a psychoanalytic understanding of these conditions can lead us back to looking carefully at relational aspects of a child’s life, most significantly with their parents.

A child and their parents are inextricably linked. When a child presents with difficulties, a perspective on the family is highly valuable. As child and adolescent psychoanalytic psychotherapists, we are training to take a careful history from the parents before embarking on work with a child. Often work with the parents is considered in place of or alongside that with the child. We work with the idea of relationships at the forefront of our minds. Relationships have a past as well as a present and so it is fundamental to work towards understanding this link. This study has looked at the meaning making of a child’s behavioural presentation by their parents. I have attempted to enrich the understanding of parents' lived experience of their child within the context of neurodevelopmental assessment, by examining the assessing clinicians' countertransference experience of the parents. It is partly through countertransference and the understanding of projection that child and adolescent psychotherapists learn about the minds of their patients.

This study has again highlighted the importance of relationships. Parents seemed to both desire and need a relationship with the clinical service. When an understanding of the difficulties was shown to be linked not just to the child but to the parent-child relationships, a trusting parent-clinician relationship was even more crucial as parents experienced persecuted feelings both from within themselves and from the clinicians.

Clinicians found that the clinic in its current format, as well as the referral pathway did not often allow them the time to develop the relationships necessary to address the frequently painful relational histories of the parent and the child. Allowing a relationship to develop in order to address these issues would of course be hugely time consuming and at odds with the 'assessment only' nature of the clinic. This leads me to wondering about neurodevelopmental diagnoses in themselves. Clinicians do not tend to diagnose when symptoms may suggest, for example ADHD, but with investigation, appear to have an attachment-based aetiology. As suggested within the literature review, the cause of neurodevelopmental conditions is not clear or simple. There is evidence for a biological basis, alongside trauma, relational and developmental elements. Is there room to consider that ADHD may be causing such significant difficulties because of factors relating to trauma experienced within the parent-child relationship? I am addressing the possibility for a less polarised diagnostic position, where relational difficulties can be seen as part of a presentation of ADHD or autistic symptoms, possibly requiring a subtype of diagnosis as Reid (in Alvarez & Reid 1999) suggested. I want to stress that attachment-based underpinnings will by no means always be the case in neurodevelopmental clinics but seems to be often the case in these complexly presenting cases in this particular clinic.

Much of the literature looking at parent experience of assessment focuses on satisfaction. It is of course necessary for NHS clinics to engage with how their client group experience their service. Measures of this are often fairly superficial. Understanding why they are satisfied or unsatisfied is a deeper more complex task and one which I have tried to make use of my psychoanalytic understanding to grapple with. This study has pointed towards two positions: firstly a need for more, more time, deeper connections, further study, and secondly a wish for less, less contact, less knowledge and a reductionist, solution-focused result. I think that I have been able to make a link between these two and the pain for both clinicians and parents when funding insists that the assessment clinic sits unhappily between these two positions. There are many news reports on dissatisfaction with or poor availability of CAMHS (The Guardian, 18th July 2021,3rd February 2022, 21st February 2022, The Times 8th Sept 2021). The solution is sometimes felt to be to ‘throw money at it’. However, I think this study has shown that these complex assessments need highly skilled teams as well as time for assessment, reflection, and careful clinical work for the whole family. It also questions the narrow pathways that press clinicians into narrow diagnostic decisions. I would also recommend that as well as reporting on dissatisfaction with services, it is important to have a wide-reaching understanding that satisfaction is a complicated position to achieve and not always the immediate priority.

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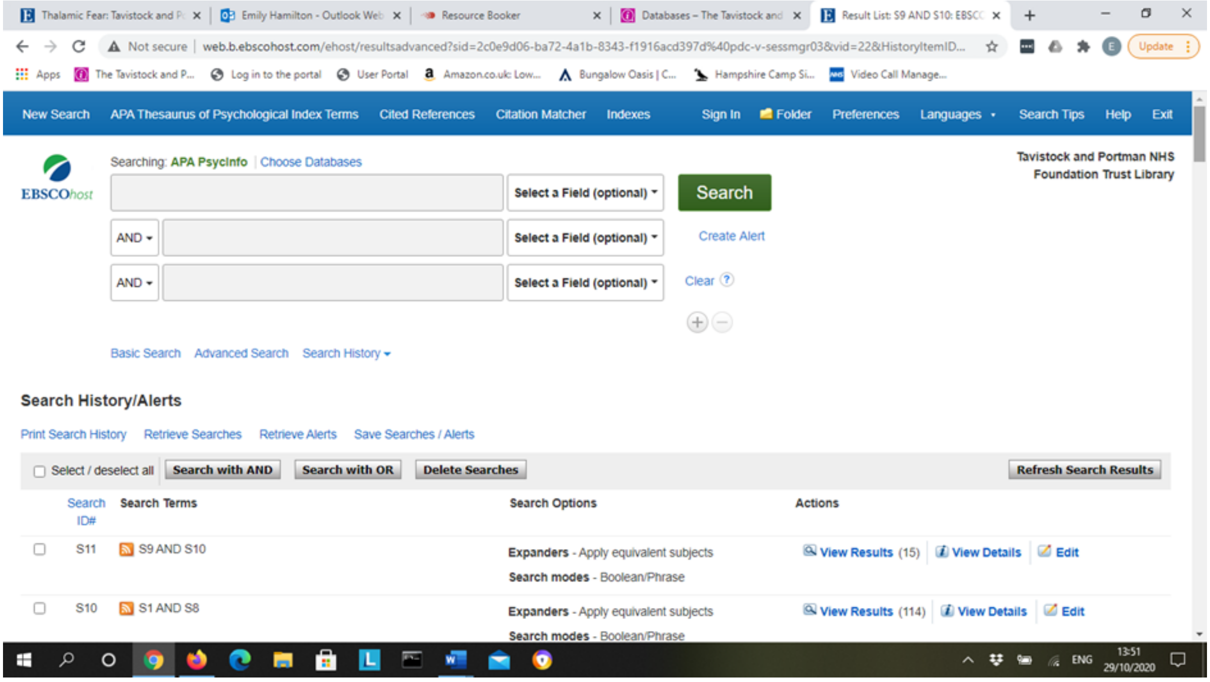
Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler & G. B. Mesibov (Eds.), Diagnosis and assessment in autism (pp. 91–110). Plenum Press. https://doi.org/10.1007/978-1-4899-0792-9_7

# Appendix A



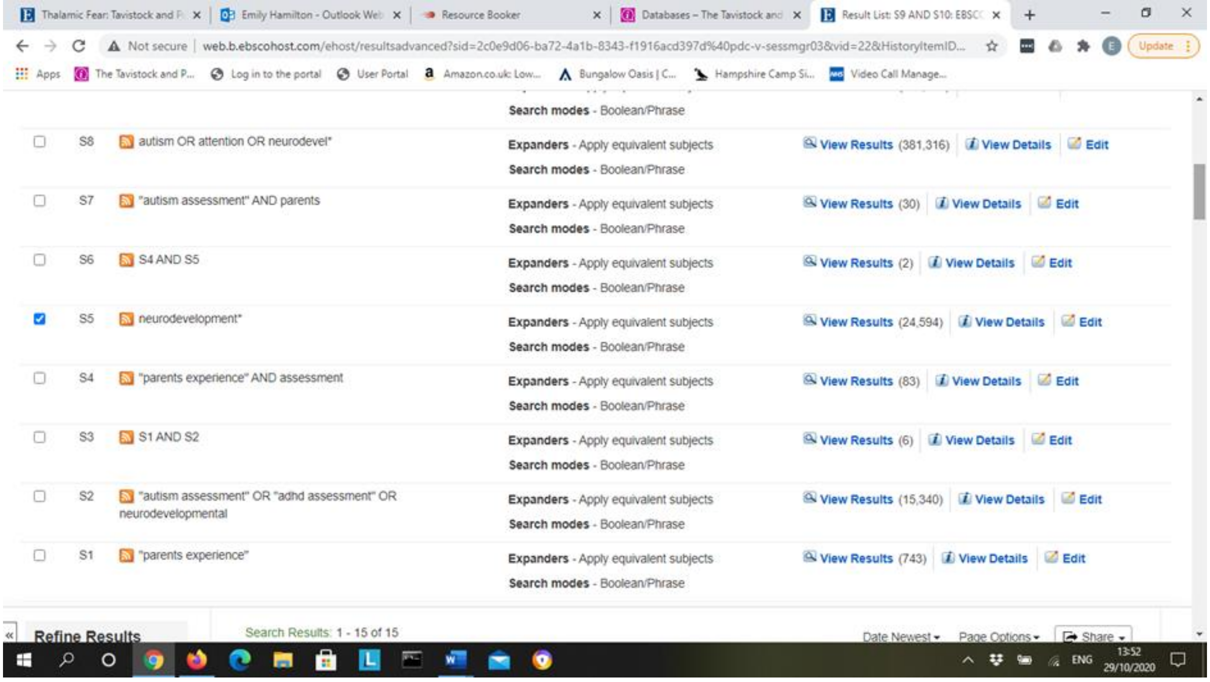
Searching: APA PsycInfo | Choose Databases

**Search History/Alerts**

Print Search History Retrieve Searches Retrieve Alerts Save Searches / Alerts

☐ Select / deselect all **Search with AND** **Search with OR** **Delete Searches** **Refresh Search Results**

| | Search ID# | Search Terms | Search Options | Actions |
|---|---|---|---|---|
| ☐ | S11 | S9 AND S10 | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (15) **View Details** **Edit** |
| ☐ | S10 | S1 AND S8 | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (114) **View Details** **Edit** |



**Search modes** - Boolean/Phrase

| | Search ID# | Search Terms | Search Options | Actions |
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| ☐ | S8 | autism OR attention OR neurodevel* | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (381,316) **View Details** **Edit** |
| ☐ | S7 | "autism assessment" AND parents | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (30) **View Details** **Edit** |
| ☐ | S6 | S4 AND S5 | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (2) **View Details** **Edit** |
| ☑ | S5 | neurodevelopment* | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (24,594) **View Details** **Edit** |
| ☐ | S4 | "parents experience" AND assessment | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (83) **View Details** **Edit** |
| ☐ | S3 | S1 AND S2 | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (6) **View Details** **Edit** |
| ☐ | S2 | "autism assessment" OR "adhd assessment" OR neurodevelopmental | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (15,340) **View Details** **Edit** |
| ☐ | S1 | "parents experience" | **Expanders** - Apply equivalent subjects<br>**Search modes** - Boolean/Phrase | **View Results** (743) **View Details** **Edit** |

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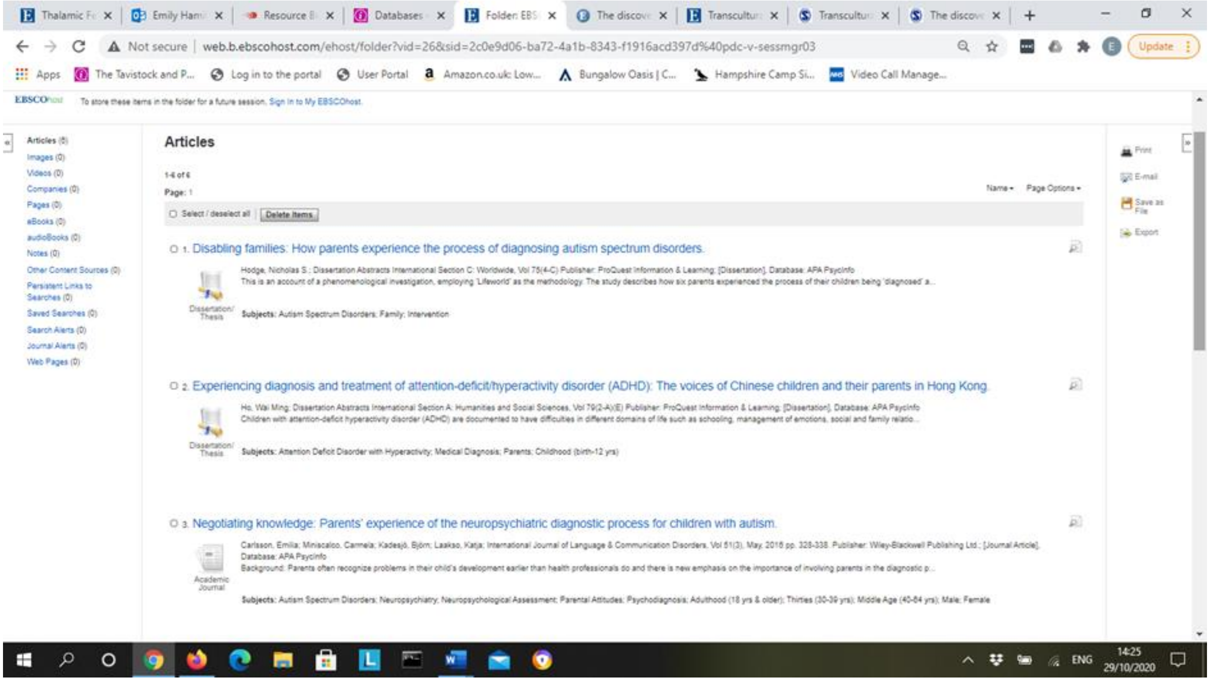


To store these items in the folder for a future session, Sign In to My EBSCOhost.

Articles

1-6 of 6

Page: 1

☐ Select / deselect all | Delete Items

☐ 1. Disabling families: How parents experience the process of diagnosing autism spectrum disorders.

Hodge, Nicholas S.; Dissertation Abstracts International Section C: Worldwide, Vol 75(4-C) Publisher: ProQuest Information & Learning; [Dissertation], Database: APA PsycInfo
This is an account of a phenomenological investigation, employing 'Lifeworld' as the methodology. The study describes how six parents experienced the process of their children being 'diagnosed' a...

**Subjects:** Autism Spectrum Disorders; Family; Intervention

☐ 2. Experiencing diagnosis and treatment of attention-deficit/hyperactivity disorder (ADHD): The voices of Chinese children and their parents in Hong Kong.

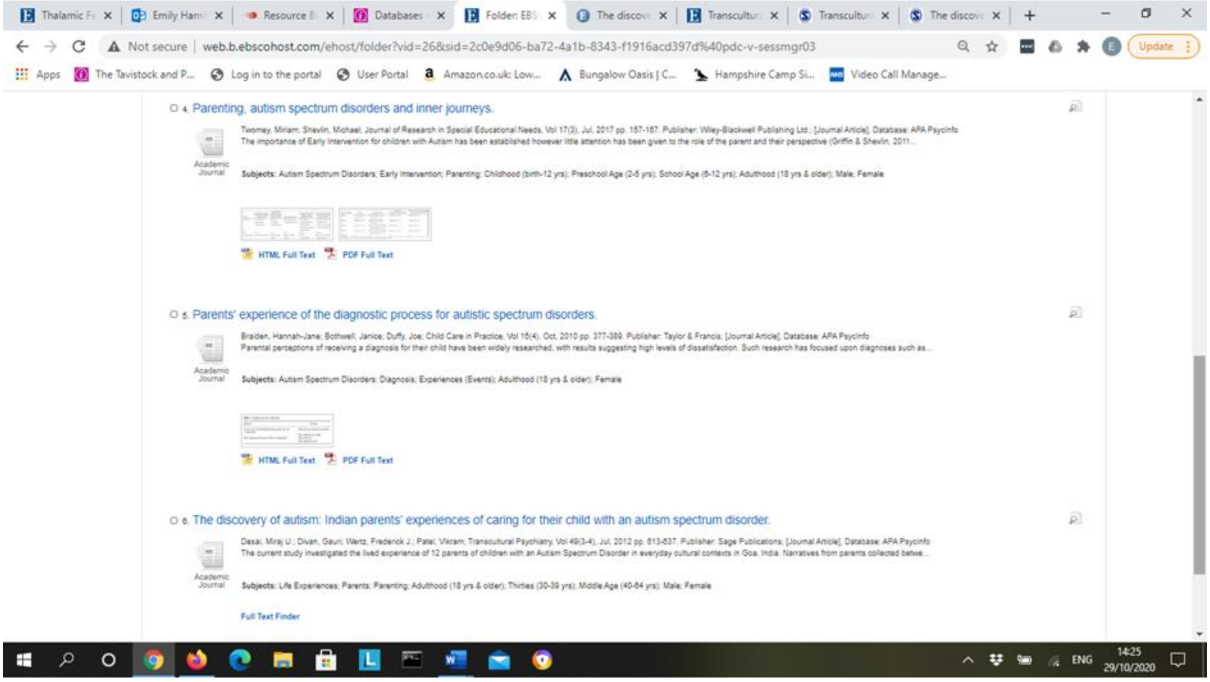
Ho, Wai Ming; Dissertation Abstracts International Section A: Humanities and Social Sciences, Vol 79(2-A)(E) Publisher: ProQuest Information & Learning; [Dissertation], Database: APA PsycInfo
Children with attention-deficit hyperactivity disorder (ADHD) are documented to have difficulties in different domains of life such as schooling, management of emotions, social and family relatio...

**Subjects:** Attention Deficit Disorder with Hyperactivity; Medical Diagnosis; Parents; Childhood (birth-12 yrs)

☐ 3. Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism.

Carlsson, Emilia; Miniscalco, Carmela; Kadesjö, Björn; Laakso, Katja; International Journal of Language & Communication Disorders, Vol 51(3), May, 2016 pp. 328-338. Publisher: Wiley-Blackwell Publishing Ltd.; [Journal Article], Database: APA PsycInfo
Background: Parents often recognize problems in their child's development earlier than health professionals do and there is new emphasis on the importance of involving parents in the diagnostic p...

**Subjects:** Autism Spectrum Disorders; Neuropsychiatry; Neuropsychological Assessment; Parental Attitudes; Psychodiagnosis; Adulthood (18 yrs & older); Thirties (30-39 yrs); Middle Age (40-64 yrs); Male; Female



☐ 4. Parenting, autism spectrum disorders and inner journeys.

Twomey, Miriam; Shevlin, Michael; Journal of Research in Special Educational Needs, Vol 17(3), Jul, 2017 pp. 157-167. Publisher: Wiley-Blackwell Publishing Ltd.; [Journal Article], Database: APA PsycInfo
The importance of Early Intervention for children with Autism has been established however little attention has been given to the role of the parent and their perspective (Griffin & Shevlin, 2011...

**Subjects:** Autism Spectrum Disorders; Early Intervention; Parenting; Childhood (birth-12 yrs); Preschool Age (2-5 yrs); School Age (6-12 yrs); Adulthood (18 yrs & older); Male; Female

HTML Full Text  PDF Full Text

☐ 5. Parents' experience of the diagnostic process for autistic spectrum disorders.

Braiden, Hannah-Jane; Bothwell, Janice; Duffy, Joe; Child Care in Practice, Vol 16(4), Oct, 2010 pp. 377-389. Publisher: Taylor & Francis; [Journal Article], Database: APA PsycInfo
Parental perceptions of receiving a diagnosis for their child have been widely researched, with results suggesting high levels of dissatisfaction. Such research has focused upon diagnoses such as...

**Subjects:** Autism Spectrum Disorders; Diagnosis; Experiences (Events); Adulthood (18 yrs & older); Female

HTML Full Text  PDF Full Text

☐ 6. The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder.

Desai, Miraj U.; Divan, Gauri; Wertz, Frederick J.; Patel, Vikram; Transcultural Psychiatry, Vol 49(3-4), Jul, 2012 pp. 613-637. Publisher: Sage Publications; [Journal Article], Database: APA PsycInfo
The current study investigated the lived experience of 12 parents of children with an Autism Spectrum Disorder in everyday cultural contexts in Goa, India. Narratives from parents collected betwe...

**Subjects:** Life Experiences; Parents; Parenting; Adulthood (18 yrs & older); Thirties (30-39 yrs); Middle Age (40-64 yrs); Male; Female

Full Text Finder

## Appendix B

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
https://tavistockandportman.nhs.uk/

Emily Hamilton

**By Email**

4 March 2020

Dear Emily,

**Re: Trust Research Ethics Application**

**Title:** What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

**Please be advised that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.**

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Best regards,

## Appendix C.

**Academic Quality** <academicquality@tavi-port.nhs.uk> Mon, Jun 22, 2020, 9:56 AM

to lucia, Jocelyn, TELSupport, me, Academic

Dear Emily

I can confirm that I have received your updated TREC documentation in light of the current crisis and that the changes have been approved. You may proceed with your research.

For information governance purposes and in line with the Trust policies, please be advised that in order to conduct research/interviews using online video conferencing you must contact TEL (copied) to set up a zoom account. With regards to privacy, please ensure that meetings with yourself and your participants are conducting in a safe environment and that confidentiality is maintained.

Your updated TREC form is attached

Kind regards,

**Mrs Paru Jeram**
Senior Quality Assurance Officer
(Research Degrees and Research Ethics)
Academic Governance and Quality Assurance (Room 259)
The Tavistock and Portman NHS Foundation Trust
120 Belsize Lane
London
NW3 5BA
Tel: +44 (0)20 8938 2699

https://tavistockandportman.nhs.uk/research-and-innovation/doing-research/student-research/

## Appendix D

**Paru Jeram <PJeram@tavi-port.nhs.uk>**

Fri, Aug 21, 2020, 1:59 PM

to Jocelyn, me, lucia, Academic

Dear Emily

I can confirm that I have received your updated TREC documentation in light of the current crisis and that the changes have been approved. You may proceed with your research. Please be advised that the Assessor has some recommendations. Please see below extract:

I don't see a problem with either the extended age range or the extended timeframe within which the interviews will be held. My slight reservation related to the fact that parents who had already been through the assessment process were now being recruited and the way in which this would happen. Specifically, they would be contacted by phone asking if they would be interested in participating, when I think a letter highlighting the study and inviting them might be experienced as less pressurised. However, it looks like all participants are being asked verbally anyway at the point when they are offered the appointment, and that this was what we approved before, so I think, on balance, I am Ok to approve these changes.

For information governance purposes and in line with the Trust policies, please be advised that in order to conduct research/interviews using online video conferencing you must contact TEL (copied) to set up a zoom account. With regards to privacy, please ensure that meetings with yourself and your participants are conducting in a safe environment and that confidentiality is maintained.

Your updated TREC form is attached

Kind regards,

Paru
**Mrs Paru Jeram**
Senior Quality Assurance Officer
(Research Degrees and Research Ethics)
Academic Governance and Quality Assurance

https://tavistockandportman.nhs.uk/research-and-innovation/doing-research/student-research/

## Appendix E.

# *Participant information sheet*

*Dear parents,*

*You are invited to take part in my research study, about parents' experience of going through a complex neurodevelopmental assessment with their child. You will find information about the project below to help you decide if you want to take part. Please get in touch with me by using the contact details below if you have any questions or want to discuss it.*

*I hope to hear back from you.*

## *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

### What's this study about?

This study aims to find out what the Complex Neurodevelopmental Assessment process is like for parents. I hope to better understand:

- ✓ What you expected and wanted from the clinic
- ✓ What it was like in the assessment
- ✓ How satisfied you were afterwards.

Hopefully this will help clinicians to meet the needs of you and your child better.

### What would be involved?

I would like to conduct an interview with you about how the assessment went. It will require A one to one interview that would most likely be conducted on the phone or via a zoom link unless the CAMHs clinic is once again able to see children and families in person and then I would hope to be able to offer a face to face interview

This interview will be about your hopes, experiences and thoughts around the complex assessment process. Please return the consent form below and send it back in the preaddressed envelope. If you have further questions please ring the CAMHs admin 02078302931 and leave me a message to call you back.

**Do I have to take part?**

No, your participation is completely voluntary. You and your child's care will not be affected by whether or not you take part in this study. You are then free to withdraw from the study without giving any reason and without your or your child's care being affected. You may withdraw up to 3 week after the date that you took part. After this time, data will have begun to be processed and analysed with other pieces of data and will not be able to be extracted.

**Who is running the research?**

My name is Emily Hamilton and I am the lead researcher on this project.

The research is being undertaken as part of my Professional Doctorate in Child and Adolescent Psychoanalytic Psychotherapy at the Tavistock Clinic, Tavistock and Portman NHS foundation Trust.

The research is running is relation to the Complex Neurodevelopmental Assessment Clinic within the Child and Adolescent Mental Health Services (CAMHS) at the Royal Free Hospital.

**What are the benefits of taking part?**

A Child Psychotherapist's focus is on how understanding a person's experience can help with some of the stress around the experience.

I hope that having the opportunity to be carefully listened to will be a good experience for you. I also hope that in sharing your experience, we can continue to make our services better.

**What are the risks of taking part?**

No. There are no risks in taking part. However, I do know that sometimes when you begin talking about something, you can find that you want a bit more time and space to think with someone. I can therefore offer a further one-off meeting if you feel you would like to think more about the issues raised in the interview. This is optional. The clinic can also sign post you to other advice services if you would like.

**What will you do with what I tell you?**

The interview will be audio-recorded and then transcribed for data analysis purposes. The transcription will be made anonymous (using false names and details) and labelled to ensure confidentiality. All of the recordings and the written material including the forms from the study will be kept in a locked drawer that only the research team have access to. Digital versions of notes or recordings will be stored on secure servers. Copies will be kept for no more than 3 years after the end of the study, and eventually destroyed, in line with University's Data Protection Policy.

It is hoped that several parents will participate.

When all the interviews are complete, the similarities and differences will be studied and written about and some direct quotes may be used. It is possible that this research or parts of it may go on to be published in academic journals to contribute to our professional understanding of how neurodevelopmental disorders are assessed. Because I plan to only interview a small number of people (around 6) there is a very small chance that you may be recognised from your direct quotes although every effort will be made to prevent this through anonymisation such as changing names, ages and particular details.

The confidentiality of the information you provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions

This study is being sponsored by The Tavistock and Portman NHS Trust and has been approved by the Tavistock Research Ethics Committee. If you have any questions you may contact Emily Hamilton (ehamilton@tavi-port.nhs.uk) or the research supervisor (lgenesoni@tavi-port.nhs.uk ). If you have any concerns about how the study is run, please contact the Dean of Postgraduate Studies at the Tavistock: Brian Rock (brock@tavi-port.nhs.uk)

**General Data Protection Regulation (2018) arrangements**

The Tavistock and Portman NHS Foundation Trust is the sponsor for this study based in the United Kingdom. I will be using information from you in order to undertake this study and will act as the data controller for this study. This means that I am responsible for looking after your information and using it properly. I will keep identifiable information about you from this study for not more than 3 years after the study has finished.

Your rights to access, change or move your information are limited, as I need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, I will use the minimum personally identifiable information possible. I will use your name and the contact details you provide only to contact you about the research study. My supervisor and I will be the only people who will have access to information that identifies you. I may be assisted in the analysis of this information by senior colleagues, but they will not be able to identify you and will not be able to find out your name or contact details.

You can find out more about the legal framework within which your information will be processed by contacting the sponsoring Trust’s Clinical Governance and Quality Manager, Irene Henderson: IHenderson@tavi-port.nhs.uk

## Sponsor of the research

This study is being sponsored by The Tavistock and Portman NHS Trust.

**This research project has been formally approved by the Tavistock Research Ethics Committee.**

# CONSENT

## *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

**Principal Investigator:**

**Emily Hamilton**

☐I have been given the Participant information sheet dated June 2020 and I have read it. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

☐I understand that this is research that will lead to a professional doctorate and may be published.

☐I understand that although all efforts will be made to ensure confidentiality, due to the small sample size of this study there is a small chance I may be identifiable to others.

☐I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the research programme has been completed.

☐I understand that I have 3 weeks from the date of my completion of the study to withdraw from the study and that after this time I cannot withdraw from the study

☐I understand that this study is voluntary and will have no immediate benefits to me or my child.

☐I understand that my interview will be tape recorded and stored securely and in a confidential nature

☐I know that I will have the chance to talk about how I found the assessment during the interview and in a further meeting should I wish to

☐I know that I can ask where to find further help should I want this

☐I agree to provide my contact details below and am happy for the researcher – Emily Hamilton to contact me in my preferred way in order to arrange an interview.

☐I understand that the interview will happen over Zoom or telephone unless the clinic is able to be reopened from the Covid-19 lockdown.

☐I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the research within the given time frame without disadvantage to myself and without being obliged to give any reason.

**Participant**

**Signed ………………………………………………………… Date ………………………………………………**

**Print name ……………………………………………………**

**Investigator**

**Signed ………………………………………………………… Date ………………………………………………**

**Print name ……………………………………………………**

**Telephone number and/or email address**

**…………………………………………………………………………………………………………………………**

**This research project has been formally approved by the Tavistock Research Ethics Committee.**

## Appendix F.

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# *Parent Interview schedule*

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## *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

### Introduction and introductory questions:

Thank you for agreeing to take part in this interview.

Remember that what you say here will have no bearing on your child's treatment. It is a confidential interview that will not be shared with other clinicians here. I will be audio recording this interview today and then transcribing it. To protect your confidentiality, I will change names and specific details. Take your time to answer. We have 50mins and can arrange a further meeting if you have more to say or would like to take about the emotional effects of the assessment or of the interview.

Finally, I am interested in what you have to say, so please answer as you see fit.

Are you ready to begin? Do you have any questions for me before we begin?

### Question 1:

**Can you tell me about the journey that has led you to the complex assessment?**

Themes and possible prompts:

What was it about your child/situation that made you think you might need to ask for help/assessment?

How did the referral come about?

Can you tell me about any preparations you made or any expectations you had of how the assessment might go?

Had you met any of the assessors that were present in the room during the assessment before that day? How did that feel?

### Question 2:

**Can you tell me about what the process of assessment was like for you?**

Theme and possible prompts:

Can you tell me what you thought about the team who did the assessment?

Were there any moments that felt particularly significant to you? That made you hopeful or worried? Can you tell me a bit more about that?

Did your child leave the assessment with one of the clinicians at any point?

What was that like for you?

Did you have a thought about what they might be doing at the time?

Did anyone of the assessors particularly stay in your mind in any way? In what they said of did or how they made you feel?

In many of these assessments, there comes a point when the assessors leave for a short time. Can you tell me what this was like?

Did you have any idea about what they might be doing?

Can you tell me about how the feedback part of the assessment was for you?

### Question 3:

### Compared to what you had hoped or expected, how do you feel about the assessment outcome?

Themes and potential prompts:

How did you feel about the plan going forward?

Can you tell me about what you would have preferred?

Were you left with anything on your mind?

Now that some time has passed, is there anything else that you would like to tell me about your experience?

Finally, thank you for participating. I hope that this study will help us better understand what it is like to be a parent in this assessment service.

This is a debrief letter. If you have any questions please do not hesitate to contact me. If you would like to have one further meeting also please contact me. I have included some other places where you can support or advice. If in the next 3 weeks, you change your mind and wish to withdraw from the study, again please contact me. I have put the last date that this is possible for you on the form.

**It should be noted that the interview questions are followed by a series of prompt questions for the interviewer's use should the participant need them, but are not to be used exactly as written in structure or order but as per the need of the individual. The fundamental purpose of using this technique is to gain access to personal, non-intellectualised, unconscious, or unprocessed experiences. By allowing a high degree of flexibility within the interview schedule, the interviewer can follow the participant's associations and not be restricted so much by any expectations or associations of their own**.

## Appendix G.

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# *Debrief*

---

### *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

If your interview has left you feeling that you might want to talk further about your experience of assessment or of parenting your child, I am happy to offer you one further meeting. There are also other outside services that can offer support

Parents Helpline is available to offer advice to parents and carers worried about a child or young person under 25. 0808 802 5544

You may have questions about a child's behaviour, emotional wellbeing, or mental health condition. You may have a child who's already been admitted to CAMHS and have questions about their treatment or want to know what to say to your GP when you visit them. Call for free Mon-Fri from 9.30am to 4pm – available in England, Scotland, Wales and Northern Ireland.

Alternatively, for some useful information about many aspects of children's mental health care, see: https://youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/

**If you change your mind and want to withdraw my interview from the study…**

If you are still within the 3 weeks from completion of the study ………………. you may contact me on the following number 02078302931 or by email Emily.hamilton2@nhs.net to withdraw.

**Finally, many thanks for taking the time to contribute to this study. I hope you have had a positive experience.**

**Appendix H.**

## *Staff Participant information sheet*

# *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

### What's this study about?

This study aims to find out what the Complex Neurodevelopmental Assessment process is like for parents. I hope to better understand what they expect and want from the clinic, what it was like in the assessment and how satisfied they were afterwards. I want to look at how staff experience parents in the assessment and what this might tell us about the parent, the child and what they might need. I hope this will contribute to developing the role of the child psychotherapist in neurodevelopmental assessment.

### What would be involved?

I'd like you to join a focus group of the 3 or 4 clinicians who have been in a recent assessment. Any students or clinicians that were observing will also be invited to join. I will facilitate a conversation about the experiences of the team during this assessment. This will most likely take place over zoom due to the Covid-19 lockdown and our inability to meet face to face. If you have any questions let me know and we can have a discussion. My email address is ehamilton@tavi-port.nhs.uk

### Do I have to take part?

No, you don't. It's entirely your choice.

You would then be free to withdraw from the study without having to give any reason. Withdrawal is time limited to 3 weeks after the group has taken place. After this time, data will have begun to be processed and analysed with other pieces of data, it will therefore not be possible to withdraw from the study.

### Who is running the research?

The research is running is relation to the Complex Neurodevelopmental Assessment Clinic within the Child and Adolescent Mental Health Services (CAMHS) at the Royal Free Hospital. My name is Emily Hamilton and I am the lead researcher on this project. The research is being undertaken as part of my Professional Doctorate in Child and Adolescent Psychoanalytic Psychotherapy at the Tavistock Clinic, Tavistock and Portman NHS foundation Trust.

**What are the benefits of taking part?**

A Child Psychotherapist's focus is on how understanding a person's experience can help alleviate some of the stress around the experience. I hope that having the opportunity to be carefully and attentively listened to will be a good and helpful experience for you. I also hope that in sharing your experience with them team, it may develop the way in which you understand each other and work together, and that in which you assess children and their parents.

**What are the risks of taking part?**

I don't believe that there are any immediate risks of taking part.

**What will you do with what I tell you?**

The focus group will be audio recorded and then transcribed for data analysis purposes. The transcription will be made anonymous through using. All the recordings and the written material from the study will be kept in a locked drawer that only the research team have access to. Digital versions of notes or recordings will be stored on secure servers. Copies will be kept for no more than 3 years after the end of the study, they will then be destroyed in line with the University's Data Protection Policy.

During the data analysis from the focus group some direct quotes may be used. It is possible that this research or parts of it may go on to be published in academic journals to contribute to our professional understanding of how neurodevelopmental disorders are assessed. Because the group is a small number of people it is possible that you may be recognised from your direct quotes although every effort will be made to prevent this through anonymisation such as changing names and particularly identifying details.

**Who is sponsoring this study?**

This study is being sponsored by The Tavistock and Portman NHS Trust and has been approved by the Tavistock Research Ethics Committee. If you have any questions you may contact Emily Hamilton (ehamilton@tavi-port.nhs.uk) or the research supervisor Lucia Genesoni (luciagenesoni@gmail.com ). If you have any concerns about how the study is run, please contact the Dean of Postgraduate Studies at the Tavistock: Brian Rock (brock@tavi-port.nhs.uk)

## General Data Protection Regulation (2018) arrangements

The Tavistock and Portman NHS Foundation Trust is the sponsor for this study based in the United Kingdom. I will be using information from you in order to undertake this study and will act as the data controller for this study. This means that I am responsible for looking after your information and using it properly. I will keep identifiable information about you from this study for not more than 3 years after the study has finished.

Your rights to access, change or move your information are limited, as I need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, I will use the minimum personally identifiable information possible. I will use your name and the contact details you provide only to contact you about the research study. My supervisor and I will be the only people who will have access to information that identifies you. I may be assisted in the analysis of this information by senior colleagues, but they will not be able to identify you and will not be able to find out your name or contact details.

You can find out more about the legal framework within which your information will be processed by contacting the sponsoring Trust's Clinical Governance and Quality Manager, Irene Henderson: IHenderson@tavi-port.nhs.uk

**This research project has been formally approved by the Tavistock Research Ethics Committee.**

## CONSENT

### *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child as a way of evaluating and developing how child psychotherapists contribute to this service?*

☐I have been given the Participant information sheet dated June 2020 and I have read it. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

☐I understand that this is research that will lead to as professional doctorate and may be published.

☐I understand that although all efforts will be made to ensure confidentiality, due to the small sample size of this study I may be identifiable to others.

☐I understand that the group audio recording and transcripts will be stored securely and confidentially

☐I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the research programme has been completed.

☐I understand that this study is voluntary and will have no immediate benefit to me.

☐I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study without needing to give a reason. There is a 3-week time limitation to this right to withdraw and that after this time I cannot withdraw from the study.

☐I understand that the group will happen over Zoom or telephone unless the clinic is able to be reopened from the Covid-19 lockdown.

**Participant**

All names and identifying details have been changed where possible to protect anonymity

**Signed** ……………………………………………………………. **Date** ……………………………………………………

**Print name** ………………………………………………………

## Researcher

**Signed** ……………………………………………………………. **Date** ……………………………………………………

**Print name** ………………………………………………………

# *Debrief*

## ***What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child as a way of evaluating and developing how child psychotherapists contribute to this service?***

**Thank you for taking part in this study!**

**I've changed my mind and want to withdraw my interview from the study.**

If you are still within the 3 weeks from completion of the study ………………(date) you may contact me on the following number 02075302931 To withdraw.

**Finally…**

If this focus group has left you feeling that you might want to talk further about your experience of assessment or working in this team, do contact staff services via Freenet, or approach [xxxxxx]  or myself and we would be happy to spend some time thinking with you about how to address this as a team.

# Appendix I

## *Focus group schedule*

### *What can we understand about parents' experience of going through a complex neurodevelopmental assessment with their child?*

Thank you for agreeing to meet today. I've asked you to join this group as part of my study into the experience parents have when they are part of the complex clinic. I am interested in what your experience might tell me about their unconscious communication to you and via you as a group.

The group will be recorded and transcribed as described in the information leaflet. Does anyone have any questions? If you are happy to continue, please sign the form and pass it to me.

As a team, you assessed Patient A in the complex clinic on X date. They attended with their Parent A.

**Question 1:**

**Can you tell me about what you remember of this assessment?**

Potential prompts:

What do you think the parent hoped to come from the assessment? What gave you this impression?

Can you tell me about your impressions of the parent whilst they were in the room with the child? And when the child left?

Can you remember looking to each other at any point during the assessment to gage the others reaction or to share a concern? Can you tell me a bit about this particular moment.

Did you get any strong feelings about the parent? Please feel assured that this is about personal feelings, whatever they may be and will be anonymised as part of the study, this is not linked to your professional judgement nor will it be linked to not linked to a judgement of your professional conduct.

When the assessment was finished, can I assume that you got together as a group to discuss the assessment?

Can you remember what the main areas of discussion were?

Did you face any dilemmas when deciding on the outcome? Can you tell me about these?

Were there particular concerns about the parent/child/family?

**Question 2:**

**Having made your decision, what was it like feeding back to the parent/s?**

How did you think the parent/s found the assessment? What gave you that impression?

Finally, were you left with any particular feelings about this assessment/family?

Is there anything you would like to add and do you have any thoughts or feelings you can share?

# Appendix J.

## Pen portrait

**Name:** P1

**Date of interview:** 26/8/20

**Time lapsed since assessment:** 2 months

**Age and gender of child** redacted

**Satisfaction with assessment? Why?** No. Not enough time spent on getting to know family. Not in person, did not meet expectations. Did not take into account previous assessments made. Felt to have made assumptions without knowing them well. Experience of blame. Disclosure that clinician would be leaving soon. However, willing to have follow up appointments and keep hoping that more change will occur.

**Key factual details of child's history:**

German/American mother/father

Highly educated parents

Only child

Unfamiliar school/parenting culture

As a young child he was 'more active'

Schools reported problems with listening and behaviour

In year 3 he had some visual disturbance – linked to intercranial hypertension

Continued unknown physical symptoms - likened to a stroke.

Severe concussion from falling off a trampoline, bleeding on the brain. Unknown severity.

Onset of much more severe OCD

Suicidal ideation

ADHD diagnosed.

4 different schools inc redacted

3 hospitals mentioned

Private paediatrician

Very expensive ADHD specialist

School counsellors.

Psychologist

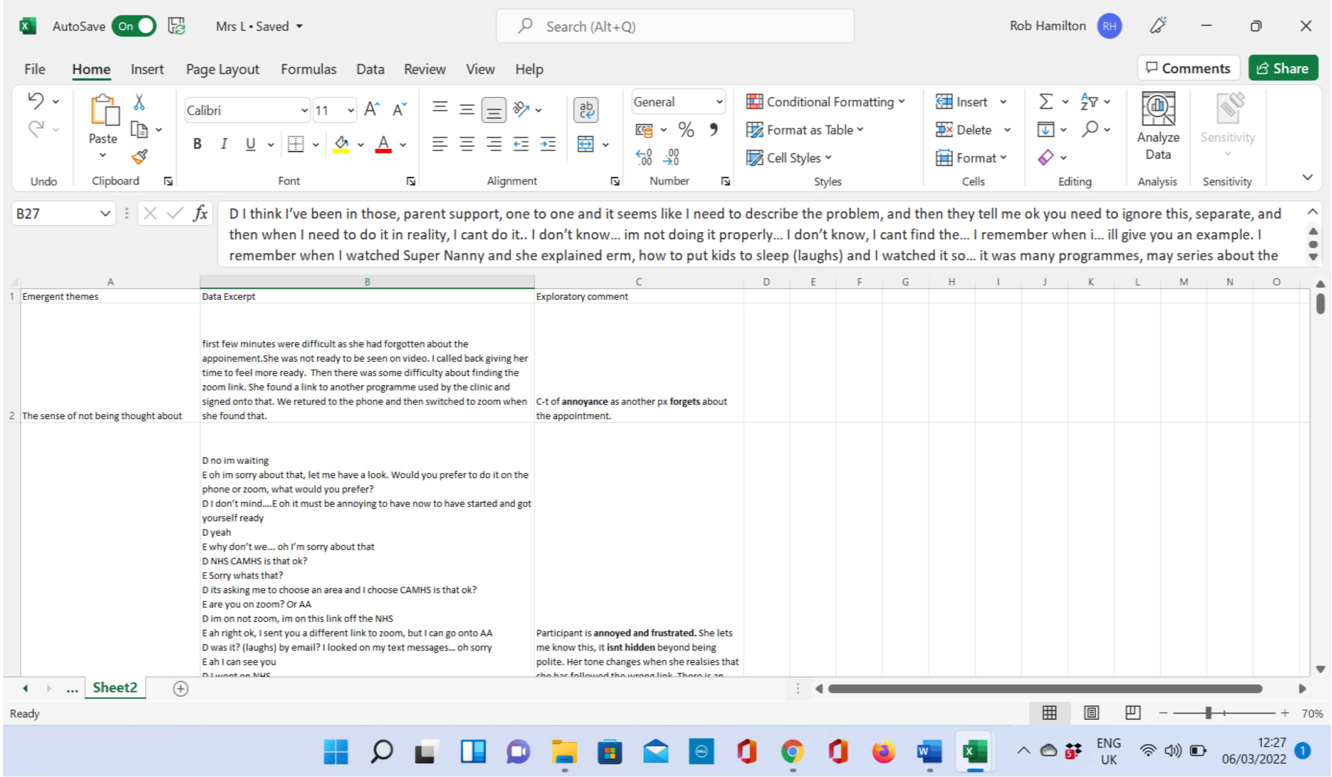
Neurologist

**Summary of counter transference in relation to participant:**

P1 arrived late to the zoom call and only after several minutes did he explain why. My gratitude for his attendance initially dampened my irritation about this but chimed with experience later on. Once we were passed the basic introductions and establishing the beginning of the discussion, P1 asked if this was relating to my phd research. The words he used were technical and began to establish a basis for comparing our levels of expertise/education and perhaps overall the power dynamic between us. It was at this point that he said that he had forgotten about the interview as well as having had to do computer updates. Again in seemed to set the dynamic of who needs whom and where does the power lie.

Generally there was an unlikeable, arrogant quality about P1 but this came alongside a strong feeling of a father desperately seeking help through his sons presenting problems. I felt that his preoccupation was the perception of whose side will the professional be on, a sort of with us or against us quality. By the end I felt almost compelled to decide whether I should advocate for further investigation and broader uptake of the historical assessments and investigations made (as P1 would wish) or to contribute to the thinking about the role of the parent/parenting in this case (as P1 said the clinicians suggested). This obviously reflects the dynamic of my role of as researcher vs my usual role of clinician, but also a sense of them and us that comes throughout the discussion.

# Appendix K.



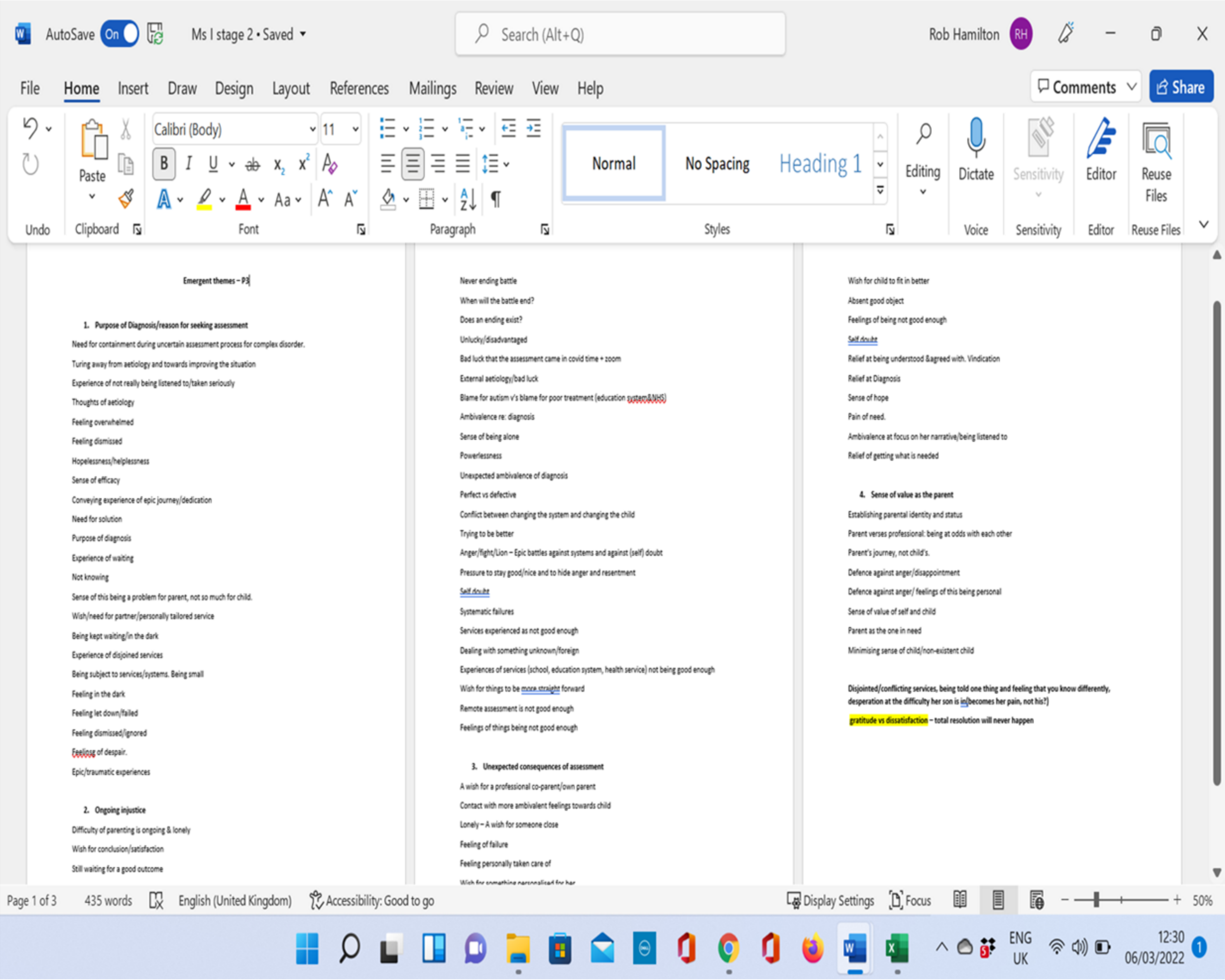
B27

D I think I've been in those, parent support, one to one and it seems like I need to describe the problem, and then they tell me ok you need to ignore this, separate, and then when I need to do it in reality, I cant do it.. I don't know… im not doing it properly… I don't know, I cant find the… I remember when i… ill give you an example. I remember when I watched Super Nanny and she explained erm, how to put kids to sleep (laughs) and I watched it so… it was many programmes, may series about the

| | A | B | C |
|---|---|---|---|
| 1 | Emergent themes | Data Excerpt | Exploratory comment |
| 2 | The sense of not being thought about | first few minutes were difficult as she had forgotten about the appoinement.She was not ready to be seen on video. I called back giving her time to feel more ready. Then there was some difficulty about finding the zoom link. She found a link to another programme used by the clinic and signed onto that. We retured to the phone and then switched to zoom when she found that. | C-t of **annoyance** as another px **forgets** about the appointment. |
| | | D no im waiting<br>E oh im sorry about that, let me have a look. Would you prefer to do it on the phone or zoom, what would you prefer?<br>D I don't mind….E oh it must be annoying to have now to have started and got yourself ready<br>D yeah<br>E why don't we… oh I'm sorry about that<br>D NHS CAMHS is that ok?<br>E Sorry whats that?<br>D its asking me to choose an area and I choose CAMHS is that ok?<br>E are you on zoom? Or AA<br>D im on not zoom, im on this link off the NHS<br>E ah right ok, I sent you a different link to zoom, but I can go onto AA<br>D was it? (laughs) by email? I looked on my text messages… oh sorry<br>E ah I can see you<br>D I went on NHS | Participant is **annoyed and frustrated.** She lets me know this, it **isnt hidden** beyond being polite. Her tone changes when she realsies that she has followed the wrong link. There is an |

All names and identifying details have been changed where possible to protect anonymity

## Appendix L



**Emergent themes – P3**

1. **Purpose of Diagnosis/reason for seeking assessment**

Need for containment during uncertain assessment process for complex disorder.

Turing away from aetiology and towards improving the situation

Experience of not really being listened to/taken seriously

Thoughts of aetiology

Feeling overwhelmed

Feeling dismissed

Hopelessness/helplessness

Sense of efficacy

Conveying experience of epic journey/dedication

Need for solution

Purpose of diagnosis

Experience of waiting

Not knowing

Sense of this being a problem for parent, not so much for child.

Wish/need for partner/personally tailored service

Being kept waiting/in the dark

Experience of disjoined services

Being subject to services/systems. Being small

Feeling in the dark

Feeling let down/failed

Feeling dismissed/ignored

Feelisg of despair.

Epic/traumatic experiences

2. **Ongoing injustice**

Difficulty of parenting is ongoing & lonely

Wish for conclusion/satisfaction

Still waiting for a good outcome

Never ending battle

When will the battle end?

Does an ending exist?

Unlucky/disadvantaged

Bad luck that the assessment came in covid time + zoom

External aetiology/bad luck

Blame for autism v's blame for poor treatment (education system&NHS)

Ambivalence re: diagnosis

Sense of being alone

Powerlessness

Unexpected ambivalence of diagnosis

Perfect vs defective

Conflict between changing the system and changing the child

Trying to be better

Anger/fight/Lion – Epic battles against systems and against (self) doubt

Pressure to stay good/nice and to hide anger and resentment

Self doubt

Systematic failures

Services experienced as not good enough

Dealing with something unknown/foreign

Experiences of services (school, education system, health service) not being good enough

Wish for things to be more straight forward

Remote assessment is not good enough

Feelings of things being not good enough

3. **Unexpected consequences of assessment**

A wish for a professional co-parent/own parent

Contact with more ambivalent feelings towards child

Lonely – A wish for someone close

Feeling of failure

Feeling personally taken care of

Wish for something personalised for her

Wish for child to fit in better

Absent good object

Feelings of being not good enough

Self doubt

Relief at being understood &agreed with. Vindication

Relief at Diagnosis

Sense of hope

Pain of need.

Ambivalence at focus on her narrative/being listened to

Relief of getting what is needed

4. **Sense of value as the parent**

Establishing parental identity and status

Parent verses professional: being at odds with each other

Parent's journey, not child's.

Defence against anger/disappointment

Defence against anger/ feelings of this being personal

Sense of value of self and child

Parent as the one in need

Minimising sense of child/non-existent child

**Disjointed/conflicting services, being told one thing and feeling that you know differently, desperation at the difficulty her son is in(becomes her pain, not his?)**

**gratitude vs dissatisfaction – total resolution will never happen**