How do parents experience “Watch Me Play!” alongside the multi-disciplinary assessment of their under-five year old’s social communication difficulties?

An Interpretative Phenomenological Analysis

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Abstract:

The project aimed to explore parents' experiences of Watch Me Play! alongside the assessment of their under-five year old for social communication disorders, including possible autism. WMP sessions were scheduled fortnightly in parallel with routine meetings comprising the assessment process within the multi-disciplinary assessment team. WMP clinicians, all child and adolescent psychoanalytic psychotherapists, conducted the WMP sessions. Semi-structured interviews were designed to take place pre-and post-intervention during which parents were asked to talk about their experiences. Clinicians were not interviewed and the WMP intervention had no bearing on the outcome of the assessment. Parents of children at the top of the existing waiting list were invited to take part: four took part in pre-WMP interviews. Two subsequently withdrew leaving two who completed the full study.

Data from interviews (four pre-WMP, two post-WMP) was analysed using Interpretative Phenomenological Analysis. The study was very small and so findings cannot be generalised but analysis of the data indicated that for some, WMP enabled greater attunement between parent and child and could contribute to greater confidence in parents' experience of relationships with clinicians and in the assessment process.

Keywords:

Diagnostic Assessment, Under-5s, Autism, Social Communication Disorders, child-led play, Watch Me Play!, therapeutic observation

Introduction

This study aims to explore how parents experience the offer of “Watch Me Play!” (WMP) alongside the process of diagnostic assessment for their under 5-year-old’s social communication difficulties, including possible autism. WMP was designed to help develop and support attachments between carers and children in foster placements and to enable carers to feel more confident in understanding and responding to their child (Wakelyn, 2019). It is now being used more widely in other contexts.

1.1 Watch Me Play!

WMP is a therapeutically informed intervention in which the parent or carer is supported to spend dedicated time with their child, closely observing their play. The child is offered a small selection of simple, age-appropriate toys which are not electronic or automated. The play takes place for a short period of time during which the carer offers their full attention. Then, the carer meets with a professional to talk about their experience of WMP: their observations and thoughts about the details that they noticed within the child’s play; how the child interacted with them during playtime and any feelings that were evoked in them as a result (Wakelyn, 2019).

Feedback from adults who have taken part, as reported in the manual, include comments such as ‘My child is calmer, and I feel more confident’ and ‘[WMP] gives an awareness of the child’s perspective’. The trialling of WMP in my service has also been successful, with reported improved scores on Goal Based Measures and increased parental confidence. This was encouraging, hence the desire for further exploration into the use of the model.

1.2 Rationale

This study has its roots in my experience as a trainee child psychotherapist within a multi-disciplinary team specialising in helping children with disabilities or complex developmental needs. My experience of conducting play-based psychoanalytic psychotherapy with this client group at times arouses in me complex, sometimes painful or unsettling, feelings. When considering this, I was struck by Galton's description of the challenge faced by a psychotherapist working with a disabled patient in acknowledging that "a patient's emotional disturbance may be treatable, but the organic disability may not." (Galton, 2019, p. 13). This statement speaks directly to the complexities for both child and family in coming to terms with a life-long condition and the repercussions of this, and those for the therapist in facing the limitations of therapeutic work alongside the belief that much can be done: we can help to make things better, but we can't offer a cure. Working as a psychotherapist who does not have a disability in this context requires particular attention to the ways in which sameness and difference emerge in the duration of a piece of work, both externally and within the transference. It is important too, that differences in terms of disability – both physical and intellectual - are not allowed to dominate at the expense of other considerations too, and disability is not the only lens through which a therapeutic relationship is considered. Rather, the complex interplay between the physical and the emotional lives of children within their cultural contexts; family lives; understanding of their gender, beliefs, fantasies and phantasies about themselves and their objects should be allowed full exploration at the same time as attending to their understanding of, and feelings about, their disability or condition. Of course, this is true of all psychoanalytic work, but I have found that the narratives that exist surrounding a child's disability can dominate, perhaps in order to defend against the anxiety, or pain aroused by the fear that a child may be disadvantaged by their condition or felt to be different from their peers.

It is important, too, to consider that for some families, the arrival of a child with additional needs is not a new experience. Siblings may also have required support, and parents themselves may be living with their own diagnosed or undiagnosed needs.

The work of developing a therapeutic relationship with a child who has a disability that affects their social communication can arouse powerful, and at times painful and frightening feelings. It can seem slow and painstaking work, as even minute changes in communication or contact and in the play can seem few and far between.

I became interested in how my experience of children's play in their psychotherapy sessions might compare with parents' experiences of playing with their child, who perhaps might not appear to respond to efforts to engage or join them in creative play. Subsequently, I learned more about WMP and was curious about how this might be experienced by this client group.

Alongside this, as I have continued to work with families who vary in their acceptance, understanding and recognition of their child's needs, I have become interested in the ways in which the journey of the assessment process – which can include long waits and inconclusive outcomes – may be experienced differently.

With reference to contemporary literature regarding assessment for autism, Christine Emanuel suggests that

> …the medical model has prevailed in recent years, portraying autism as a cluster of specific decontextualized behaviours or a concrete thing that somebody has, rather than an experience one lives. (2015, p. 54)

This seemed to me to resonate for all children who are referred to my service for assessment for developmental disability. I wondered if families whose children are undergoing such assessment feel a tension between the use and experience of diagnostic labels, which may offer helpful insight and a community of understanding but may also be experienced as a homogenising of that which is complex and highly personal.

In this project, I hoped to combine these two areas of interest to investigate whether the observational, child-centred approach of WMP adds to the experience of learning about a child's needs through diagnostic assessment.

1.3 Observation of diagnostic assessment

I observed a diagnostic assessment within my service to inform the planning of this project. It is important to note that the period between initial referral and the offer of an initial meeting frequently exceeds a year: a significant amount of time to wait. In this case, the family whose assessment I observed had been waiting for over a year. The initial assessment meeting was accompanied by a keen sense of anxiety about the process and the possible result combined with a feeling of relief that the process had begun. In the short period of time allotted for this meeting, the discussion between clinicians and family covered the wider political climate surrounding diagnosis and aetiology; the family's cultural context; the subsequent varied understanding and concerns amongst family members alongside descriptions of the everyday lived experience of the child and their family.

I became aware of a heightened anxiety as the end of the meeting approached: perhaps as the family were faced with a further period of waiting while the assessing team conducted further exploration and discussion. The questions that the parents asked became more personal and implied greater anxiety about the child's immediate presentation and their developmental trajectory. Parents asked more about what they might be able to hope for in terms of improvement in their child's verbal communication and increase in interactions with them and their siblings as their child got older. I was reminded of Susan Reid's comment that

> .. for parents to feel that they are not really interesting to their children and that they have no real impact on them... is to feel real despair. (Alvarez & Reid, 1999, p. 17).

Within this meeting, the child was given space to play and explore the room. Some of these activities were led by the clinician, some were directed by his own desire to investigate, or perhaps to seek sensory feedback from the unfamiliar setting. Clinicians drew attention to this at times during the assessment meeting and I wondered whether this would have been incorporated differently or extrapolated on by the family if they had been taking part in WMP alongside this meeting.

1.4 A note on use of terminology

In the research question and introduction above I have referred to assessment for both social communication difficulties and autism as the diagnostic pathway followed by participants in this study is concerned with social communication disorders alongside neurodiversity. As the final diagnostic tool used in the team is the ADOS, I have focussed the literature review searches on autism specifically, as this is the foremost, and most prevalent, diagnosis that is considered and given to children seen by the assessment team.

There exists debate regarding which of the terms Autism, Autistic Spectrum Disorder and Autistic Spectrum Condition is the more appropriate. In this paper, I have used the term autism, in line with current practice in my service. The terms neurodevelopmental and neurodiversity are also used in my service to describe the differences and variation in behaviour and presentation in our patients. For clarity, I have not used these terms routinely here as they are used to refer to a range of conditions (such as ADHD, dyslexia etc) whereas this study focuses on autism.

1.5 NICE guidelines for post diagnostic support

NICE guidelines (2013) state that post diagnosis, clinicians should consider:

> … specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. (2013, CGI70, p. 40)

My hope is that this study will contribute to discussions about the role of play based interventions in assessment and early treatment; whether play-based interventions like WMP can also add to the personalisation of the assessment process and, following this, if it can be used to support parents to continue to feel attuned and curious about the ways in which their developing child experiences and explores their world.

2 Literature Review

Introduction

This literature review aims to provide an overview of the current research and thinking in relation to the key themes of assessment and early intervention, the value of a therapeutic observational approach in supporting parents with both the diagnostic journey and their relationships with their child. I hope to demonstrate that the current literature supports the validity of WMP as an appropriate intervention for parents who are navigating the complexities of parenting a child with additional needs due to its focus on developing attunement and supporting parents to make sense of their child's play, and therefore to feel more able to think about their lived experience. I hope to situate this study within the current field of research; to identify where there is scope for future exploration and to consider how this study may helpfully contribute both to the body of work which exists concerning parents' experiences of assessment for autism and also to the growing number of studies that are evidencing the benefits of the WMP approach.

I have briefly outlined the strategies employed below which facilitated this.

Strategy

This study is predicated on a psychoanalytic approach and so psychoanalytic concepts were at the forefront of my mind when I conducted the search for relevant literature and in my arrival at the selection below. I began with searches of relevant, largely psychoanalytic, journals for relevant studies, and then broadened the search from the results from this by using the database PsychInfo, which focuses on literature from the psychological field of study. This was complemented by references taken from bibliographies from books recommended by supervisors and colleagues and those offered by the teaching on my course of study. This literature review is, therefore, narrative rather than systematic.

I have grouped the selection under four overall headings. Each of these is divided into smaller sections which present the findings under specific themes relevant to this study, as listed below:

1. **Autism: aetiology**
2. **Autism: psychoanalytic perspectives**
3. **Assessment for social communication disorders and autism spectrum conditions**
    - 3.1 Assessment of autism by services
    - 3.2 Studies of parents' experiences of assessment
4. **Watch Me Play!**
    4.1 WMP: an overview
    - 4.2 Therapeutic observation
    - 4.3 Facilitating Reflection
    - 4.4 Early intervention following assessment

These are followed by my conclusions from the literature reviewed and my thoughts about the contribution that this project may make to the existing literature.

2.1 Autism: aetiology

Leo Kanner first studied patterns of what he called “fascinating peculiarities” (1943, p. 217) in his paper “Autistic Disturbances of Affective Contact”. He arrived at the term “early infantile autism” in 1949, describing the characteristics of this condition as follows:

- Profound withdrawal from contact with people
- Obsessive desire for sameness
- Skilful and even affectionate relation to objects
- Mutism, or the kind of language which does not seem intended to serve the purpose of interpersonal communication

Kanner pinpointed the emergence of “early infantile autism” as early as the “second half-year of life”, (1949, p. 418) and argued for its inclusion in psychiatric nosology as a distinct condition. He described the parents of the children with early infantile autism unfavourably, commenting that “maternal lack of genuine warmth is often conspicuous” and describing fathers who “rarely step down from the pedestal of sombre adulthood to indulge in childish play”. (1949, p. 422). His highly critical view of the parents of the children he met, and his references to their “emotional refrigerator” experiences and demeanours (1949, p. 423) in particular, makes for shocking reading for a modern-day audience.

The later model of the “triad of impairments” was presented by Gould and Wing in 1979, who proposed that in order for criteria for a diagnosis of autism to be met, difficulties in three areas were evident: social communication, social interaction and social imagination or rigidity of thought. (Gould & Wing, 1979).

The triad of impairment was then replaced in the DSM-V criteria for diagnosis of autism when it was updated in May 2013 (American Psychiatric Association, 2013). The three areas were consolidated into two categories of symptoms: persistent deficits in social communication/interaction, and restricted, repetitive patterns of behaviour. A new diagnosis of social communication disorder was added to recognise disabilities of social communication without repetitive, restricted behaviours. There are five criteria for consideration before a diagnosis is given, which are offered with illustrative examples:

- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted repetitive patterns of behaviour, interests, or activities as manifested by at least two of the illustrative examples given
- Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies later in life)
- Symptoms cause clinically significant impairment in social, occupational or other important areas of functioning
- These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder

NICE Guidelines (2013) stipulate that findings from the assessment and information gathered are considered against these by a multi-disciplinary team, along with clinicians’ views concerning severity and subsequent levels of support required for each area. Where previously separate categories of autism existed (autistic disorder, Asperger’s syndrome, childhood disintegrative disorder, pervasive developmental disorder - not otherwise specified), these were now consolidated under the term “autistic spectrum disorder”.

I present an overview of key psychoanalytic perspectives on this in the section below.

2.2 Autism: psychoanalytic perspectives

In her 1929 paper, “Personification in the play of children,” fourteen years before the publication of Kanner’s fist work, Klein describes children who are not capable of play “in the proper sense” (1929, p. 193). Klein observes:

> They perform certain monotonous actions, and it is a laborious piece of work to penetrate from these to the unconscious. When we do succeed, we find that the wish-fulfilment associated with these actions is pre-eminently the negation of reality and the inhibition of phantasy. In these extreme cases no 'characters' ever appear. (1929, p. 193)

Today, we may imagine that these children might have been referred for an assessment for autism. Klein’s phrase “play in the proper sense” deserves some consideration. What is play “in the proper sense”? How do we gauge when a child is playing “properly”, or when it is something else that they are doing? The OED definition of the verb play (2023) indicates two key components of play: the engagement in an activity for recreation or pleasure rather than any other purpose, and to participate in something.

Klein describes her work with Dick, a 4-year-old, in her 1930 paper “The Importance of Symbol-Formation in the development of the Ego” (Klein, 1998), who similarly was

> …indifferent to most of the objects and playthings around him and did not even grasp their purpose or meaning. But he was interested in trains and stations and also in doorhandles, doors and the opening and shutting of them. (1998, p. 224).

It would appear from Klein's description of Dick that his interest in trains, stations and doorhandles perhaps did give him pleasure, but Klein questions whether this activity is one of active participation, or whether it is in the service of defensive avoidance of anxiety. To the modern reader, Dick's interest is one of adhesive identification (Bick 1968, Meltzer, 1975): The hard object is not a symbol, or a shared space for play, but functions as a second skin tool. (Bick, 1968). This description of limited play perhaps resonates for clinicians and parents who wish to engage children in creative reciprocity and have perhaps felt unable to reach them, or not allowed in.

Klein perceives that Dick's apparent lack of interest in or relation to anything around him is indicative of a lack of development in his capacity to symbolise. She says

> His lack of interest in his environment and the difficulty of making contact with his mind were, as I could perceive from certain points in which his behaviour differed from that of other children, only the effect of his lack of a symbolic relation to things. The analysis had to begin, with this, the fundamental obstacle to establishing contact with him. (1998, p. 225).

Through the course of the analysis, Klein formulates that as he begins to establish a relationship with her, his anxiety lessens and his capacity to symbolise is strengthened, along with his incremental desire to make himself understood. His curiosity and interest in exploring his environment through play also grows and he becomes more able to use toys and playthings to communicate his unconscious phantasies.

The value of psychanalytic psychotherapy in helping children with autism was further explored by Meltzer and colleagues in the period 1960-1970 during which psychoanalytic work was undertaken with a number of autistic children. In the first section of his book “Explorations of Autism”, Meltzer presents the findings from this period. He differentiates between what he calls the “autistic state of mind proper” (1975, p. 6) and mental functioning which is “in a sense outside the autism proper – what we see as the residues of autism”: in other words, the autistic and the non-autistic parts of a child’s psychic functioning. He summarises the factors that contribute towards personality development in a child with autism as:

> High intelligence, sensitivity to the emotional state of others, liability to depressive pain of a massive sort, minimal sadism and consequently minimal persecution; possessive jealousy; the children are highly sensual in their love, and prone to endless time-arresting repetition of the joy and triumph of possession. (1975, p. 10)

He uses the term “dismantling” to describe the attack on linking made within this time-arresting, or avoidance of the sense of the passing of time, differentiating this from Klein’s splitting processes in that it is a passive process rather than an active one on the part of the child. He further states that this capacity for

> …suspending attention, which allows the senses to wander, each to its more attractive object of the moment. This scattering seems to bring about the dismantling of the self as a mental apparatus, but in a very passive, falling to bits way. (1975, p. 12)

Through the analytic work, Meltzer arrives at the formulation that

> …it was necessary for the therapist to be able to mobilise the suspended attention of the child in this autistic state, in order to bring it back into transference contact. (1975, p. 15)

The defences that some autistic children employ to avoid the outside world has been further explored since Klein and Meltzer by Frances Tustin who, in her work first published in 1992, "Autistic States in Children", describes autism as "a massive not-knowing and not-hearing provoked by traumatic awareness of bodily separateness." (2021, p. 12). She observes how children with autism seem interested in hard rather than soft toys, which she calls "autistic objects" (2021), resonant of Klein's observations of Dick. Tustin explains that these hard objects are valued for the sensation that the child experiences when holding or gripping them, rather than for any symbolic meaning or transitional support. They are employed as a kind of "autogenerated hypnosis which makes the child feel safe and comfortable." (2021, p. 20). Tustin notes that although these are intended to help avoid the experience of bodily separateness, in actuality they can result in a child "becoming increasingly separate, alienated and cut-off." (2021, p. 20).

In her paper "Prenatal Trauma and Autism" (2001), Suzanne Maiello explores Tustin's thinking regarding the impact on both mother and baby of traumatic events during pregnancy and delivery from which autistic retreat may originate and its links with maternal emotional and mental states. In her clinical material, Maiello observes in her patient (a mother and baby daughter who had been at risk of miscarriage) the "adhesive at one-ness" that Tustin calls "dual unity" (2001, p. 7); a defence against the anxieties inherent in being separate. She draws a parallel between Kanner's "refrigerator" mothers and Tustin's image of the "frozen child", noting that both need to be helped to "thaw". Maiello says that "reciprocity begins where fusion ends" (2001, p. 117), suggesting that therapeutic support can enable both to be able to take up a position from which to be able to see, think about and to relate to the other.

In her book "Live Company", Anne Alvarez describes the need for the therapist to "reclaim" the child (1992) who is withdrawn or seeming not to know that the therapist is there at all. When reflecting on her work with Robbie, an autistic boy she saw in treatment for a number of years, Alvarez says

> … what sometimes seemed to be the rather passive implications of the function of containment, with its notions of thoughtful reverie, seemed to leave something to be desired… I began to feel a need and urgency to be more active and more mobile than with other patients… I began to feel that I, as the mother or father in the transference, had to chase after him, not because he was hiding, but because he was deeply lost. It seemed to me that my function was to reclaim him, as a member of the human family because he no longer knew how to make his own claims. (1992, p. 54).

Graham Music stresses the significance of imitation in enabling a child to foster a sense of self. He describes his realisation whilst working with one autistic girl, that what was required

> …was not sophisticated technique, did not require complex interpretations, and certainly did not at this stage require any push towards reparative or depressive feelings. It did seem to need me to watch for and mirror and exaggerate any signs of liveliness, and echo these as strongly as she could

> manage, which in turn led her to be able to resonate with my aliveness. (2007, p. 13).

Play became possible for Music and his patient after she had gained a more robust sense of self, which had been fortified by her experience of his close attention and careful response.

Didier Houzel (2008) also emphasises the need to acknowledge the more lively, non-autistic part of the child. He differentiates between “autistic reactions” and “the autistic state” or structure (2008, p. 135). He explains that autistic reactions can become apparent when any child experiences heightened anxiety such as in separations, but in response to this, the child can quickly turn to others or to utilise transitional objects which

> …can be used as a vehicle for his projections and on which he can base the imaginary scenarios that help the mind to tolerate frustration (2008 p. 135).

Houzel suggests, for children in autistic states, every object is experienced as a rival “baby in the nest”, which engenders overwhelming anxiety and distress which requires the child either to ignore these rivals by denying “the existence of otherness”, or to eliminate them by destroying or throwing them away. Houzel cites this as the reason that it is “Impossible” for an autistic child to play.

Maria Rhode describes how this can feel disheartening for parents, who can find this puzzling and difficult to relate to. She describes her work with three-year-old “Isabel” and her parents:

> … [Isabel] tapped repetitively on hard surfaces, like the table or the humming top. She had no interest in the dolls' house, and seemed frightened of the teddy in her box, as though anything evocative of another baby might pose a threat. Isabel needed our total involvement. She once cast a delicate, tentative glance over her shoulder in her parents' direction, became disheartened by their preoccupied expression as they talked, and then remained impossible to engage. Mr and Mrs G responded eagerly when I described the delicacy of her glance: "she's always been like that": I could see how easily a vicious cycle of mutual discouragement could have arisen. (2013, p. 29).

The ”vicious cycle of mutual discouragement" occurs when both parent and child's attention is misaligned, and neither feels emotionally received by the other.

Paul Barrows cites Trevarthen and Aitken in his advocacy for the role of emotional engagement of the kind exemplified by Music above, over and above intervention targeted at speech and language, which is often at the forefront of intervention design for children with autism given the frequent concerns about language development. Trevarthen and Aitken say

> For more children with greater problems in communication, an approach that addresses the underlying interpersonal problem is more effective. Emotional engagement and joint attention appear to have a more fundamental role in furthering language development in autism than instrumental use of language. (Barrows, 2008, p. 97).

Barrows links this to Winnicott's emphasis on the importance of play, particularly his suggestion that

> Where play is not possible, then work done by the therapist is directed towards bringing the patient from a state of not being able to play into a state of being able to play. (Barrows, 2008, p. 38).

The literature promotes the view that through the use of a psychoanalytic approach, an understanding of the child's anxieties and defences can emerge. This can inform understanding of all parts of their presentation: autistic and otherwise. However, this is not to discount neurobiological assessment: indeed, William Singletary argues that the convergences between neurobiology and psychoanalysis allow us to see autism through a new lens. In his 2015 paper, he proposes an integrative model which presents autism as a "neurobiological disorder of experienced environmental deprivation, early life stress and allostatic overload". Singletary suggests that autism

> …is a potentially reversible neurodevelopmental disorder in which neurobiological factors- not poor parenting- interfere with the child caregiver interaction. The infant experiences deprivation of growth-promoting parental input even though it is available. (2015, p. 81)

Singletary proposes that a child's experience of social isolation causes them to feel threatened, which may lead to overwhelming feelings of stress or anxiety which have subsequent psychological and biological elements and outcomes. He posits that psychoanalysis can be a tool for research within an integrative model:

> ...looking at the autism literature through the lens of what I have found to be the ASD child's central experience…we can now discern a remarkable confluence of findings from multiple disciplines, making possible the construction of an integrative model of ASD as a neurodevelopmental disorder with psychological as well as behavioural components that are potentially treatable and even perhaps preventable. (2015, p. 83)

Singletary proposes three primary factors though which the convergences between psychoanalysis and neurobiology can be organised:

1) Neurobiological dysfunction leads to disruption of child caregiver interactions, resulting in the early deprivation of crucial social and emotional experiences
2) Stress both psychological and biological plays a central role
3) Neuroplasticity is a fundamental element in both pathways leading to ASD as well as in the capacity for significant adaptive development and positive change in children with ASD

He concludes:

> Targeting the basic factors in the proposed model overcoming environmental deprivation through increasing social and emotional engagement, diminishing anxiety and psychological stress, along with reducing allostatic load seems to be of significant value in facilitating therapeutic change in ASD, likely by promoting adaptive neuroplasticity. (2015, p. 100).

The psychoanalytic approach towards the aetiology and features of autism focuses on the recognition of autistic states as defences against anxiety. The view put forward by writers such as Tustin, Meltzer and Reid is that the aetiology of autism is made up of multiple differing causes; including the complex interplay between a baby's neurological impairment which may perhaps prevent them from accessing early nurturing or cause them to withdraw along with maternal depression or despair at feeling that their baby's perceived unresponsiveness to their effort to engage them. (Alvarez, 1992). As Singletary's study demonstrates, this approach can complement the more neurobiological position to examine the emotional, medical and the environmental aspects of the condition. As Alvarez recommends, ongoing clinical observation and research is required to avoid “simplistic, linear aetiological theories of autism” (1992, p. 187).

2.3 Assessment for Social Communication Disorder and Autism Spectrum Conditions

Although the NICE guidelines for assessment as outlined above are clear, what

constitutes an assessment can vary depending on the resources, staff and procedures available to those who are conducting the assessment, whether this is done privately or within an NHS setting.

However, all assessment comprises a dialogue between family and clinician(s) and is of course inevitably informed by the experiences and position, internal and external, of all involved. I begin here with discussion of the research which focuses on services’ assessment of autism before considering what current literature offers in terms of understanding the impact of a child receiving a diagnosis on their parents and the parenting offered subsequently to the child.

2.3.1 Assessment of autism by services

Howlin and Moore (1997) surveyed nearly 1300 parent members of autistic societies across the UK to ascertain their views about the process of diagnosis. The survey focused on the length of time taken before results were offered and parents’ views of the adequacy of both the assessment and any subsequent help that was offered to them. They predicted that diagnoses given earlier (i.e. to younger children) would result in greater parental satisfaction and that certainty of diagnoses rather than the use of terms such as “traits” or “features” would be better received.

Parents were asked to complete an anonymous questionnaire having been contacted through national support groups listed by The National Autistic Society. 53.1% of forms were returned. The study lists the factors that determined parental satisfaction as: area of residence, child’s age at diagnosis, delay between first seeking help and confirmation of diagnosis, child’s current age, and final diagnosis given. This correlates with the authors’ initial hypotheses. They report that most participants had concerns about their child’s delayed language or social development yet over 35 percent were “told either not to worry or to return only if problems persisted” (1997, p. 154). They describe how only 40% of those that continued to seek further assessment were given a formal diagnosis. For some, no diagnosis was made until individuals were in their “20s or even 40s” (1997, p. 155). Howlin and Moore conclude that it is “hardly surprising, therefore, that families’ views of the diagnostic process were far from complimentary”. (1997, p. 155). They recommend that early concerns expressed by parents should be taken seriously and referrals to specialist services must be more promptly carried out. They also recommend that labels such as “autistic features” should not be offered unless absolutely necessary and that diagnosis should be accompanied by the offer of direct help and support to families.

An online UK survey was conducted in 2015 of over 1000 parents whose children had received a diagnosis in the previous 15 years in order to investigate opinions about the process of attaining a diagnosis for autism. (Crane, Chester, Goddard, Henry & Hill, 2016). This study was an adaptation and extension of the original Howlin and Moore 1997 study above which had previously been the only to have taken place in the UK. Parents were asked about their initial concerns regarding their children; the different professionals encountered during the diagnostic process; the time taken including waiting time; their own reactions to the diagnosis and experiences of post-diagnostic support.

The survey found that parents typically encountered a 3.5 year period between the first contact with a professional to express a concern and the child's receipt of a diagnosis. This length of time was much the same as in the 1997 survey. Both surveys found that the length of time between first contact and diagnostic results had a negative correlation with overall parental dissatisfaction with the process as a whole. It was also noted that many participants valued support that was offered with their particular child in mind, rather than generic information about autism, and clinician sensitivity about communicating the results of the diagnostic assessment. Satisfaction with post-diagnostic support was found to be a strong indicator of parental satisfaction with the whole process.

The findings point towards recommendations of more expedient, streamlined processes with early access to tailored information and ongoing support is likely to result in more positive reported experience. However, the study includes a helpful reminder that it is not always possible for clinicians to provide "an accurate diagnostic label at an early age" (2016, p. 159).

It is interesting that this study does not extrapolate on what constitutes parental satisfaction in terms of their ongoing relationship with and parenting of their child, but rather focuses on the clinician-parent relationship.

In their 2019 study, Sheldrick, Frenette and colleagues ask “what drives the detection and diagnosis of ASD?” of children in the USA. They aimed to evaluate the effect of the different contributing components of clinical judgement, screening tools, parental concern and shared decision making which lead to diagnostic assessment whilst a child is receiving Early Intervention. Analysis of quantitative and qualitative data pertaining to the 1,654 children who took part in the study indicated that where most screening tools are designed to facilitate early detection and diagnosis, the goal of ensuring continued family engagement with services was of equal importance to clinicians. They suggest that

> Failure to recognise the importance of maintaining family engagement through the screening and referral process risks creating a disconnect between front-line staff who provide care and researchers who implement evidence-based protocols… the potential for such disconnects between parents, providers and screening highlights the need for shared decision making to promote and maintain family engagement. (2019, p. 2316).

This study concludes that expression of concern and implementation of screening tools are interdependent processes:

> .. on the one hand, parents and providers’ concerns were found to influence both initiation of and engagement with screening. On the other hand, their concerns were found to change over time in response to additional information, including the results of screening instruments. (2019, p. 2317)

This study is concerned primarily with the application of assessment tools which identify symptomology in the same vein as Gould and Wing's triad. St Clair and colleagues (2007) suggest that parents recognise that something is wrong with their child long before these tools are applied, and therefore greater understanding about what triggers these concerns in the first place would increase understanding about who is likely to develop autism, and how best to support both child and family. (St. Clair, Danon-Boileau, Trevarthen, 2007, p. 21).

Reid and Alvarez comment that

> ... a psychiatric diagnostic checklist for autism may confirm the presence and severity of autism, it cannot tell us what it is like to be autistic or what it is like to live with a child with autism. (1999, p. 14).

Stella Aquarone expresses a similar view, suggesting that as autism is a disturbance of the intersubjective life of the child it will inevitably impact those who live with them (Acquarone, 2018, p. 22). The literature that examines the offer of diagnostic assessment and post-diagnostic support does not appear to consider how assessment could be best used to understand more about the impact of autism on family intersubjectivity.

Furthermore, Howes, Burnes and Surtees (2021) suggest that whilst the majority of the literature concerning the carrying out of diagnostic assessment seeks to explore the development of relevant tools and efficacy of process, "the experience of those involved in the diagnostic process is often neglected" (2021, p. 450). They suggest that

> Although it is crucial to understand how parents experience the diagnostic process, we also need to understand the experiences and perceptions of professionals and people with autism themselves. (2021, p. 450).

They emphasise the impact that professionals' experience may have on diagnostic outcomes, and indeed accuracy. Their systematic review of qualitative research aimed to help with the recognition of facilitating and preventative factors experienced by assessing clinicians. Interestingly, amongst the reported barriers were perceived weaknesses in diagnostic tools, particularly in considering atypical presentations. Some professionals reported described a view that "subjective impressions" were being objectified by some tools. (Karim et al., 2014, as cited in Howes, Burns & Surtees, 2021, p. 454).

The literature highlights the importance of timely response to parental concerns about their child's development and suggests that services consider their clinicians' level of professional experience and the use of clear diagnostic terms and ongoing support.

2.3.2 Studies of parents' experiences of assessment

In her 1998 paper "The significance of trauma in work with parents of severely disturbed children…", Klauber reminds us that for some parents, the process of diagnosis can be a traumatic one, both in recognising that there are concerns to be addressed and then in waiting for, and receiving, what she calls "professional judgement". Klauber proposes that for some families, this experience can have a profound impact on their future attitudes towards and relationship towards seeking help, suggesting that

> ...professionals may be experienced as a minefield filled with the fear of judgement and criticism, with dreadful stirrings of the memory of noticing something was wrong, seeking diagnosis or encountering professional dispute and dogma (1998a, p. 89).

Current literature regarding the impact of diagnosis on parents' responses and experiences during and following assessment seeks to explore this picture and to ascertain which factors contribute or may alleviate parental stress.

In their 2019 study, Reed, Giles, White and Osborne seek to establish which aspects of the diagnostic process most strongly affected parental reactions. They list other studies that research the impact of other diagnoses of disability and life-long conditions on parental functioning and suggest that diagnosis and its subsequent effect on the parents may be crucial in determining resulting outcomes for children. They differentiate between "unresolved" and "resolved" parental reactions to diagnosis, contrasting parental mental states in each. In this study, they pull together two possible reasons for different parental responses to their child's ASD diagnosis: the pre-existing parental functioning, and the parental response to the diagnostic process itself.

Reed and colleagues were particularly interested in parental responses to the speed of diagnosis, both actual and perceived. Key findings indicate that mothers who experienced longer diagnostic process rated the speed "poorer" but tended to be more "resolved" in their reaction to the diagnosis. They suggest that this seems to be at odds with parents’ expressed desire for quicker diagnosis: i.e., parents may experience frustration at the length of the assessment during the process but also report a greater sense of resolution as a result but perhaps do not connect these two experiences. The study reports that those who experienced a speedier diagnosis also reported higher levels of parental stress, although it was not possible to gain a picture of what happened during the process which may have affected their perception of its speed. The study concludes that longer diagnostic periods and better clinician interpersonal skills are associated with greater parental feelings of resolve post diagnosis.

One longitudinal study, (Jacobs, Steyaert, Dierickx and Hens, 2019), carried out in Belgium, aims to explore how parents viewed and experienced their child’s ASD diagnosis over a period of one year. The study was designed in response to evidence that, although existing studies had focused more closely on challenges presented by an ASD diagnosis and the need for post-diagnosis support, they also suggested that parents’ views may shift over time. The parents of 11 boys were interviewed at 3 time points to show evolution of parental views and experience of ASD diagnosis before, immediately after and at 12 months. Key themes at each time point were identified. The first interviews (Time 1) resulted in the theme “expecting certainty and exculpation,” which captured participants’ desire for clarity about what was going on with their child and their hope that diagnosis would absolve any feelings of parents’ responsibility for their child’s condition. The second (Time 2) resulted in the theme “vulnerabilisation of child” as parents whose children had received an autism diagnosis spoke of how they felt that diagnosis made their child more vulnerable. The third interviews took place a year after diagnosis. These produced the theme “pragmatism and some disappointment” as parents expressed some pragmatism but were also disappointed in post-diagnostic services. Discussion of these themes considers how families felt at the outset that diagnosis may reduce possible feelings of blame for their child's presentation. The study notes the "clinical trajectory" (2019) of movement from feelings of blame to a more explicit sense of the fragility of the child, towards a more pragmatic position at the time three, where "ASD" was now the cause of child's behaviours, rather than parents, child or something else. Similarly, it stresses the need for parents to access support from clinicians to help with possible exacerbated feelings of responsibility for ensuring their child's successful development and future. The study concludes that at the outset, parents hope that diagnostic process will offer certainty and remove guilt. The authors suggest that addressing parental concerns at each clinical consultation throughout the diagnostic process may lead to better alignment between clinician and parent and increased satisfaction throughout the "clinical trajectory" for both parties.

Mueller and Moskowitz (2020) suggest that training for parents in developing skills to support their child with ASD often overlooks the impact that a child's autism can have on the parents' mental health. Their study, which was conducted in America but does not specify where, aims to evaluate a parental training programme which combines Cognitive Behavioural Therapy and Positive Behaviour Support approaches. Data collection via questionnaires comprised of scaled measure took place at weekly intervals throughout the eight weekly sessions of the intervention. Although there were limitations to the study in that only three mothers took part and no fathers, and the data was solely parent-reported and so it is not possible to generalise from this, the results indicate that participation in the programme demonstrated statistically significant improvements in their children's behaviour and a decrease in what the study deemed to be unhelpful parental beliefs.

In their study, Deschamps, Ibanez, Edmunds and colleagues (2021) examined parental stress levels before a diagnostic assessment, finding that parents who were concerned that their children may have autism reported higher levels of parenting stress than those with children with other developmental concerns, or children with no concerns. Participants were taken from a community-based project and completed a battery of questionnaires which were subsequently analysed. Whilst the study shows that parents concerned about autism experienced significant worry and challenges caring for their child and advocates for intervention to be offered before diagnostic evaluation, it also recommends further research is carried out with larger and more diverse sample groups over longer periods of time.

Voliovitch, Levanthal, Fenick and colleagues (2021) conducted an RCT to ascertain levels of parental stress prior to diagnostic evaluation for ASD. This study complements DesChamps and colleagues' 2020 study. DesChamps and colleagues did not include the impact of the assessment and was conducted with a sample group of predominantly white, university educated parents. Voliovitch and colleagues conducted the study with a sample group of 317 “urban” parent-child dyads from minority racial groups. Parents were asked about extent of their worry regarding child's development and also about past or current supports from various family services and questionnaires were completed regarding child adaptive skills, parental stress levels, parental perception of social support and parental coping strategies. Despite demographic differences, parenting stress was associated with measure of parental functioning and level of worry about their child. Conversely to the earlier study no association between parenting stress and ASD severity in this study is established. The findings instead suggest that parental strengths and supports were critical to levels of parenting stress experienced for all parents and recommended that factors of parenting stress, social support, parental worry, should be assessed before the completion of child's diagnostic assessment to ascertain the impact of a diagnosis of ASD on parental stress.

Anderberg and South (2021) research whether providers can predict parent reactions to the assessment process and therefore modify their feedback to mitigate for possible parental adverse emotional reactions to the news of a diagnosis for their child. They stress that the moment of receipt of a diagnosis can feel like a turning point, the experience of which can have lasting repercussions on family relationships and aspirations and perceptions of the child's future. They refer to other studies which have reported on frequent parental reactions to diagnosis, such as validation or relief, or anticipation of further support, or feelings of worry and hopelessness, depending on how informed or prepared the parents felt as a result of the process.

The study is informed by three hypotheses which were based on their summation of previous literature. Firstly, that parents who were more decided that their child would meet diagnostic criteria would have more positive reactions to the diagnosis; secondly, that parents who knew more about autism before the feedback session would leave feeling more prepared than those who felt they knew less beforehand; thirdly, that parents' emotional reactions and level of prior knowledge would have an impact on the clinician's interpersonal manner and the amount of information they offered in the feedback meeting. These hypotheses are supported by the data which emerged from the mixed method study. Feedback from providers also confirms that offering a balance between emotional support and information and resources was critical for a positive outcome to a feedback meeting. The study recommends that families are prepared adequately for the meeting, that appropriate support and information is given while they are on a waiting list in order to reduce anxiety about the possibility of receiving a diagnosis. They also suggest that families are asked about their reasons for seeking a diagnostic assessment in order that the process can be tailored appropriately to their needs. Anderberg and South recommend that future research is conducted across a more racially and socio-economically diverse sample group, and that gathering information during the process rather than retrospectively (as here) would better prevent bias caused by overall feelings about the process in hindsight.

Overall, the literature suggests that parental experiences of assessment are impacted by the levels of support, information and preparation that is offered in advance of and during the process. The correlation between clinician/parent dialogue, shared information prior to assessment and improved parental resilience and more a positive emotional response is suggested, which, in turn, has a beneficial impact on parent-child relationship and care.

Klauber says that

> The importance of developing potency in strengthening egos of deprived and disturbed children is equally important for parents whose flattened sense of their capacity to parent their children needs bolstering and strengthening as well. (1998b, p. 48).

The literature reviewed also evidences that it is important to heed Anne Spoladore's warning that

> Efforts to understand the relationships between autistic children and their parents may be seen by such professionals as new attempts to blame the environment for the disorder. Likewise, many parents… find it difficult to consider that some autistic symptoms can be psychogenic. Such an attitude can negate the emotional experience of the autistic individual and hinders the possibility of improvement through a therapeutic relationship. (2013, p. 23).

The literature shows that clinician sensitivity is paramount if parents are to be helped to navigate their child's diagnosis and their own emotional response to it.

2.4 Watch Me Play!

Other interventions utilise child-led play and are designed to foster parent-child attunement and reciprocity and thus have elements in common with WMP. The Tavistock five-session model of parent-child psychoanalytic psychotherapy, for example, designed as a brief early intervention facilitated by a child psychotherapist, also supports the parent-child relationship. Maria Tselika and Lida Anagnostaki's work in this model which took place in Athens (2019) is relevant to this study. Their work took place with "Jason", a boy with autism, and his family, in the context of their Day Care Centre. This pilot study led them to the conclusion that the model could be used generally as a starting point for all therapeutic work offered to families and children with autism.

However, WMP differs from other interventions of this kind in that it focuses on the dedicated space for the parent to reflect with the WMP clinician about their experience of their child’s play. WMP also includes the combination of allocated times that the parent and child play at home in addition to sessions with a clinician. I give an overview of the intervention below.

2.4.1 WMP: an overview

The main elements of WMP are undivided attention for short periods of time, two-three times a week. During this time, parents talk to their child about their play and then are invited separately to reflect on this with a WMP practitioner. The WMP introductory guide outlines 5 steps of this process (Wakelyn, 2023):

i) Getting started
ii) Letting your child take the lead in the play
iii) Watching your child play
iv) Talking with you child about their play
v) Talking with another adult about your child’s play

While the child is playing, the parent is encouraged to notice what their child is doing, to describe it and to wait to be invited to join in. Parents are helped to ensure that the beginning and ends of WMP time with their child are clearly demarcated, eg with putting the toys away, or with a song or statement to let them know that this time is different from other playtimes or shared activities. After the child has played, parents meet to think about their experience with a trained WMP practitioner, to share their thoughts, feelings and observations about their child’s play. WMP is a flexible approach but it is suggested that, where possible, 6 sessions be offered, followed by a review. Goals can be set before the sessions begin and reviewed later. It is advised that practitioners access supervision to reflect on their work and how best to support the family.

Wakelyn (2019b) explains that WMP grew out of her learning from conducting a therapeutic observation with a young child and his foster carer with their wider network. In particular, she emphasises the ways in which observations can “bring alive” (2019b, p. 12) the child’s experience in the minds of adults. Wakelyn says

> Holding the child in mind is a fundamental aspect of parenting that can be profoundly impacted by early disruptions. When the adults are able to take in what the child shows in their play, the child is less alone with distress or anxiety, and the impact of early trauma can be mitigated. (Wakelyn, 2019b, p. 13).

The WMP model aims to support parents to hold their child in mind in this way. The WMP manual (Wakelyn and Katz, 2020) outlines the steps involved in the intervention and its intended use. The authors emphasise the simplicity of the process and materials required. They summarise the key points underpinning its premise as below:

- child-led play promotes development and learning
- Showing that you are interested helps your baby or child to focus
- Watching closely helps you to hold in mind what your child says and does
- Adults thinking together about a child’s play helps him or her to feel understood

The manual emphasises that WMP is built around child-led or baby-led play. Parents are encouraged to notice and follow their child, allowing them to explore the toys or materials that have been selected. Parents are discouraged from being too directive or attempting to teach their child through play, and are reminded that although play may seem repetitive, paying close attention can allow parents to notice small changes and developments that may otherwise have gone unnoticed. Wakelyn and Katz give suggestions for ways in which parents could talk to their child about their play and also remind that gaps or silences do not necessarily have to be filled with speaking. Throughout the manual, sections are illustrated with quotations from caregivers who have completed the intervention, such as “not intervening can lead to a story being told by a child through play.” (Wakelyn & Katz, 2020, p. 13).

The second part of the manual offers further information about the WMP approach and how it was initially aimed at supporting children and infants in temporary foster care. (Wakelyn, 2019a). Guidance regarding times when WMP may not be an appropriate intervention (such as when ongoing care proceedings or safeguarding procedures are being undertaken) is provided. More detailed information regarding child-led play including guidance for clinicians offering or hoping to train in the model is included, as well as example case studies.

Current research into WMP is underway in Italy, where the Associazione Italiana di Psicotherapia Psicoanalitica (AIPPI) have established a research collaboration to evaluate the method. In Japan, research is underway to evaluate the implementation of WMP within children’s homes and adoptive and fostering families. This is being carried out by Waseda University Research Institute for Children’s Social Care, Tokyo. Provisional research has been presented at conferences in both countries but is not yet in publication (Wakelyn, 2023).

In a recent study, Koenig and colleagues explore the feasibility and acceptability of offering WMP online to families with children under seven with developmental delay (Koenig et al, submitted for publication). They used framework and thematic analysis to evaluate this. Prior to WMP, participants were given the manual, diary sheets and logs and then took part in WMP with a trained clinician. Baseline measures were collected and then again after eight weeks. Participants were emailed weekly and reminded to complete the accompanying logs. The intervention was found to be feasible and acceptable, and the outcomes indicated that parents perceived improvements in their relationships with their child. Parents initially found WMP challenging but then more positive as they began to feel that it was beneficial. The offer of the intervention online was well received. Significant factors reported were the relationship with the practitioner through which parents felt supported and understood rather than blamed or criticised. Koenig and colleagues say:

> Beliefs about what play should look like changed for most parents throughout the intervention. This process can be understood as the generation of new meanings and narratives. Exploring parents’ narratives about their child’s capabilities, play and parenting in the first WMP session and comparing these to the values behind WMP may guide the practitioner in how to scaffold subsequent sessions. (Koenig et al., in publication, p. 26).

Barriers to engagement included demands such as being a working parent, other childcare commitments, and the necessary time commitment, although the flexibility of the model did help with this. Logs were also reported as the key burden for families. Overall, Koenig and colleagues conclude:

> Findings underscore WMP’s potential for families of children under seven with a developmental delay, suggesting a need for adapted design. (in publication, p. 29).

Koenig and colleagues’ study paves the way for further research into the use of WMP with a wider range of patient groups and for further consideration into different ways that it could be delivered.

WMP could be a well targeted intervention for children with social communication difficulties as it supports parents and carers to pay close attention to the minutiae of a child’s communication through play. The opportunity to reflect on this with a practitioner also offers support for parents and carers in to think about behaviours which may otherwise leave them feeling that their child is hard to reach.

Currently, there is no further completed research into the use of WMP for supporting families undergoing developmental assessment for their child. Koenig and colleagues’ study is encouraging as its target population is similar; however it is does not investigate explicitly the experience of parents taking part in the intervention, neither does it locate their experience of WMP at a particular point in time within the family’s ongoing relationship with services and developing understanding, formalised assessment and diagnosis of their child’s needs. This suggests that there is scope for my study to complement their findings in adding further understanding to the efficacy of WMP with this population.

2.4.2 Therapeutic observation

The value of therapeutic observation is a key principle of WMP. Parents are supported to pay close attention to their child and are supported to think about their own emotional responses to watching their child play and are encouraged to feel confident to note the ways in which they might have been surprised by new aspects of their child's interactions, however small.

Bion's concept of containment (1962) is relevant here. He suggested that an infant evacuates frustration: unprocessed, unwanted feelings (beta elements) for the mother to receive and then transform these via alpha- function. The state of being open and receptive to these beta elements he called reverie: "the psychological source of supply of the infant's needs for love and understanding." (1962, p. 36).

Bion proposes that

> If the mother fails in [her capacity for reverie] then a further burden is thrown on the infant's capacity for toleration of frustration. (1962, p. 37).

The infant experiences containment through the process of alpha-function which takes place when the mother is able to sustain a state of reverie. Thus, she observes her child, receives their projections and returns evacuated beta elements in digested form.

In their paper "Attachment and reflective function: their role in self-organisation", Fonagy and Target propose a similar concept. They suggest that a child acquires the ability to mentalise through their early relationships. They say

> The development of children's understanding of mental states is embedded within the social world of the family, with its interactive network of complex and at times emotionally charged relationships, which after all constitute the primary content of early reflection. (1997, p. 681).

They outline the stages of an infant's growing capacity to reflect. The infant develops this capacity via the interpersonal interactions offered by caregivers. Fonagy and Target propose that is it through this that the child's attachment security is established:

> The child who looks for a way of managing his distress identifies in the response of the caregiver a representation of his mental state which he may internalise and use as part of a higher order strategy of affect regulation. (1997, p. 685).

As with Bion's concept of containment, Fonagy and Target explain how limitations in the development of reflective function can occur due to the child's "biological vulnerabilities" (1997, p. 696) or factors which may impede

…parent's capacity to respond to the child in ways which promote a mentalizing model of self-other relationships. (1997, p. 696).

Therapeutic observational approaches such as WMP aim to support parents in the development of these capacities.

Didier Houzel (1999) describes how therapeutic observation can be used as a precursor to child psychotherapy. His therapeutic team use Bick's model of observations conducted in the home, during which an observer visits a new baby and their family weekly with the aim of learning about an infant's early life, his development and growing relationships with the world around him. The observer then compiles detailed notes and then discusses these with a group of psychoanalytically trained colleagues. Alongside this, parents meet monthly with a consultant to think about their child's development and to consider any questions.

Houzel emphasises the three types of receptivity which an observer conducting this work must develop: perpetual (e.g., an awareness of the behaviour of the child and those nearby – gesture, vocalisation etc); emotional and empathic (the experience within the observer himself in response to that which is observed) and unconscious receptivity: the countertransference.

Houzel says that developing one's unconscious receptivity is the most difficult skill, as it requires

> .. tolerating having an experience of situations which may at times be extremely painful, irritating, depressing, without having an understanding of them, and without foreclosing them by a move into action (leaving early, giving advice, opinions, judgments etc) (1999, p. 45)

With the support and containment of the supervision group, the observer can think retrospectively about the meaning within this unconscious communication.

In their study, Kelly, Slade and Grienenberger (2005) test the hypothesis that levels of maternal reflective functioning could be used to predict the quality of mother-infant communication and infant attachment. They explore the links between maternal behaviour and maternal reflective functioning, in particular

> The notion that a mother's ability to regulate her infant's fear and distress are linked to her capacity to make sense of her child's internal experience. (2005, p. 301).

They suggest that this might in part explain intergenerational attachment difficulties. This study, part of a longitudinal project, measures parent-infant attachment relationships of 45 mothers. Measures used were the Parent Development Interview

(PDI), The Strange Situation and the Atypical Maternal Behaviour Instrument for Assessment and Classification (AMBIANCE). As predicted, results showed that there was a negative correlation between negative maternal caregiving and both maternal reflective functioning and infant secure attachment. Kelly et al refer to Fonagy and Target's above study, and state that

> The mother must not merely demonstrate that she understands the child's anger, fear, or distress, however, but must also communicate this behaviourally in a way that serves as a model for the child, thereby indicating that he can have a similar experience of mastery… with some caregivers, there is a failure of affect mirroring… with others, there is an abundance of affect but a lack of necessary calmness and confidence on the part of the caregiver… with some parents there are critical breakdowns in both mirroring and mastery, as infant distress becomes a trigger for the caregiver's own unintegrated and chaotic internal states. (2005, p. 307).

Kelly and colleagues state that this has implications for early intervention, plans for which should consider parents' readiness for the "psychological burdens of parenthood" (2005, p. 309) and the range to which parental emotional needs impact interactions between parent and child. They advocate for psychotherapeutic work for parents, saying that

> Not only can the parent-infant or child psychotherapist demonstrate an interest in the mental states of the patient, but she can also show the same curiosity regarding the mental states of the child. The parent and the therapist can struggle together, within the context of a safe and containing relationship, to understand the child's thoughts, feelings, motivations, intentions and behaviours. (2005, p. 309.)

In their paper “Sewing on a Shadow: acquiring dimensionality in a participant observation”, Blessing and Block (2009) suggest that participant observation is an “intermediate areas – neither pure observation, nor psychotherapy – a potential space where something transforming may take place.” (2009, p. 22)

Whereas within Bick’s training model, the observer does not participate in the activities or discussion in the home whilst observing, yet neither are they a fly on the wall. They are present, and emotionally responsive, without being drawn in as the purpose of the observation is to learn about relationships (Allnutt, 2011, p. 7).

In contrast, Maria Rhode (2007, p.208) lists important functions of a therapeutic observer:

- Receiving, containing and validating/verbalising concerns from both parents and children
- Making links between parents and child
- Embodying a third party, regulatory function
- Facilitating the inclusion of all people present
- Modulating separations
- Experiencing aloneness and rejection

These are true of the role of the WMP clinician who, crucially, facilitates discussion with the parent about their experience of watching their child play.

In her paper, “What is psychoanalytic about the Tavistock Model of Observing Infants? Does it contribute to psychoanalytic knowledge?” Isca Wittenberg describes Bick’s revelation that regular, systematic observation

> ...opened up a whole new dimension to understanding the most primitive anxieties and defences against them, the intimate inter-connection between soma and psyche and the interactive processes between mother and baby. (2008, p. 5)

Wittenberg links Winnicott's observation that a baby cannot be considered outside of the context of its immediate caregiver in her description of an observer's gathering of a parent's fantasies, what she calls their "pre-transference" (2008, p. 11) to their baby: their hopes about how he might develop." In addition to this, Wittenberg draws our attention to the ways in which an observer may witness suggestions of a parent's own unworked through infantile desires and anxieties, reawakened by having a baby, and how these may impact the ways in which a parent relates to their baby – such as "rejection, harsh treatment, distancing or over-indulgence" (2008, p. 12).

Similarly, Wakelyn (2020) promotes these values in her discussion of therapeutic observation, suggesting that it can be "helpful in circumstances where something has got in the way of a connection between a parent or primary caregiver and the baby" (2020, p. 34).

She continues that

> An observer who remains actively interested in a baby, however fragile or disabled the baby may be, models curiosity and hopefulness in a way that can be encouraging for parents and professionals alike. For clinicians, the focus on trying to understand what the baby's experience might be like can help to find a position alongside parents and professionals without being experienced as critical or intrusive. (2020, p. 34).

2.4.3 Early intervention following assessment

Delion (2000) promotes the application of Bick’s method to the observation of babies at risk of autism, proposing that observation can support both diagnosis and act as early intervention. A multi-disciplinary team including child psychiatrists trained in Bick’s method formed an Autism Federation which aimed to promote collaboration, training and research into this area with particular interest in the therapeutic alliance with parents.

Delion says that

> There is no doubt that the parents of a child with autism, as well as the child, formerly faced something of an obstacle course in the search for appropriate treatment, which could leave them seriously bruised. Parents often speak about the gap between diagnosis and treatment as though it were a ‘black hole’ of despair into which the child and family were plunged. (2000, p. 86).

Observations offered to families enabled clinicians to feedback to multi-disciplinary discussion to inform treatment pathways and contextualise diagnostic decisions. Delion concludes with his belief in the value of infant observation, stating that

> This method allows one to explore the baby’s symptomatology, but also to investigate the present quality of his interactions and to make links between pathological symptoms, the baby’s internal world and the family history. (2000, p. 90).

A 2014 systematic review of early intervention for infants at risk of autism (Bradshaw, Mossman-Steiner, Gengoux and Koegel, 2014) suggested that at that time, early detection methods were advancing but development of interventions was still limited. The authors reviewed nine studies which reported on measures of parent positivity and observed gains in infant development and social communication concerning infants under 24 months.

They define “Early Intervention” as

> A variety of services, some of which are empirically validated, some of which are empirically validated and while others carry minimal empirical support. (Stahmer et al., 2005., in Steiner et al., 2014).

They cite examples of therapies and programmes accessed by families, such speech and language therapy, sensory integration support and others which are informed by ABA approaches, or which include developmental psychology- informed elements. (2014, p. 779).

The study emphasises the need for intervention prior to the age of two, citing evidence of accelerated brain development at this time. Evidence of observed prodromal symptoms of autism before the age of two is also cited. They note that eight of the nine studies reviewed included some component of parent-led intervention, and that the majority of participants across all studies were “highly educated” (2014, p. 790) and half had an older sibling with ASD or another developmental disability, and so prior knowledge of may have informed the ways in which the carried out the interventions.

A 2015 parallel, single-blind, randomised trial conducted in Manchester and London compared the results of parent-mediated intervention and no intervention for infants at risk of autism. (Green et al., 2015). The intervention was based on the Video Interaction for Promoting Positive Parenting programme (VIPP) and focused on close attention to infant behaviour and communication of intentions. Here, VIPP was increased from 6 to 12 sessions with the possibility of a further six additional booster sessions. Therapists conducted sessions in the home with parents and infants and all sessions were video recorded to obtain assessment data which was measured using the Autism Observation Scale for Infants (AOSI). It was felt that the trial demonstrated that intervention of this kind is feasible as all participant families completed the intervention successfully. Results demonstrated that the "intervention effects were spread more generally across parental, infant dyadic, symptom and cognition outcomes" (2015, p. 139) than other parent-mediated interventions which showed greater effects on areas such as parent and child dyadic behaviours rather than "more distal ASD symptoms".

Jones et al (2017) also examine the impact of parent-delivered early intervention with infants at-risk of ASD. Their study also considered the role of older siblings with ASD, referencing studies in which suggest that differences in underlying social attention may be evident before the child meets diagnostic criteria for autism.

They proposed that an early intervention focussed on developing infants' social attention may "alter developmental trajectories".

Their study was a randomised clinical trial for infants at risk of ASD between 9 and 11 months. They measured social attention at 1 months and then with a follow up assessment at 18 months. They explain that the intervention was designed to stimulate neural systems pertaining to social interaction which included the capacity to respond to another.

Parents were trained in the manualised programme “Promoting First Relationships” by a PFR provider who discussed the video-taped interactions between parent and child; particularly highlighting parenting strengths and responses to the infant’s cues.

The results of the trial were reported to be broadly in line with the initial predictions; that

> ...compared to infants who were only assessed and monitored, infants who received the intervention from 9 to 11 months of age showed indications of improvement in neurocognitive metrics of social attention at both 12 and 18 months, with a relatively large effect. (2017, p. 969).

Overall, the study concludes that early intervention of this kind, along with others geared at reducing emerging symptoms, could be “a powerful tool for boosting key attentional mechanisms underlying social communication development in this population.” (2017, p. 970).

Maria Rhode (2018, p.193) describes how infant observation focuses on preverbal communication. She outlines the possible experience of parents who may feel rejected and hurt by a baby who appears unresponsive to them, in contrast to parents and infants whose games and reading of each other’s cues is both a source of reciprocal pleasure and from which language develops.

Rhode suggests that parents can feel doubly invalidated, by their baby’s lack of responsiveness but also by their own lack of certainty about their perceptions of this, and lack of validation from professionals. (2018, p. 194). Rhode describes this phenomenon as “the vicious cycle of discouragement” (2018, p. 202), suggesting that

> Young children with autism [have] their own lack of responsiveness and difficulty in turning to other people [which] can sometimes make parents and professionals feel exhausted and discouraged. Their hopefulness can be undermined, and they can become less able to respond to what are often minimal cues. (2018, p.202).

Rhode proposes that support from an observer may help to allay this, and as in Delion’s experience, an observer’s contributions can enrich information gathered from more structured assessment tools. Rhode gives an interesting example of the case of one child, who was observed to engage in social referencing multiple times during the course of an observation, despite the fact that his results according to the CHAT (Checklist for Autism in Toddlers) which had been administered previously did not indicate that he was capable of following someone else’s gaze. Rhodes reminds us that

> The prognostic validity of the CHAT is linked not to what a child can do in optimal circumstances, but to what he or she does do when tested. The implication must be that at least some children in the high-risk category of the CHAT have capacities that they do not show (2018, p. 206)

Callanan, Ronan and Signal (2019) conducted an empirical case study which also examined the possible role of parents in early intervention. Their study aimed to evaluate the Parent-Child Relationally Informed Early Intervention which was developed from clinical application of Attachment Theory. The manualised programme aimed to utilise constructs such as Maternal Insightfulness, Parent

Embodied Mentalising etc. and relied on parents remaining open and responsive to child's developmental demands – sensory, cognitive, physical etc. A follow up Parent pack issued comprising of battery of measure indicated preliminary support and results suggested possible increased insightfulness of parents, although they acknowledge that the sample group consisted of four families only, so further investigation is necessary.

Whitehouse and Green (2021) also employed the VIPP in their study, conducted in Melbourne and Perth, Australia, in which 104 infants between 9-14 months of age took were randomised to receive intervention plus usual care or usual care over a period of 5 months. This study showed that those who received the intervention demonstrated symptom reduction in early childhood and reduced likelihood of diagnosis at 3 years. However, the UK newspaper The Guardian, (Sample, in press, 20 Sept 2021) reported some criticism of this study, raising questions about whether children who have improved with such intervention will still be eligible for ongoing support that they may need if they no longer meet diagnostic criteria for a formal diagnosis.

Tim Nicholls, head of policy at The National Autistic Society, is reported to have said:

> ...it's important that any future study into very early intervention does not seek to lessen 'severity' – early intervention should be about supporting autistic people with the biggest challenges that they face... for effective research to be done in this area in the future, autistic people must be involved at every stage. (in press, 2021)

Professors Green and Whitehouse published their response to this in the same newspaper a few days later. They reiterated that intervention works with parents, and not the infant at all, and rather than “opposing” autism, their study

> …cherishes neurodiversity by attending to and understanding it, giving equal opportunity to these infants for an adapted and responsive social environment. (Whtehouse & Green, in press, 2021).

They argued for a needs-based system for resource allocation, proposing that “what really needs to happen as a result of this work is an examination of the very concept of clinical diagnosis and the way it is made”.

This debate encapsulates the tensions evidenced by the literature I have reviewed here between what the reaching of diagnostic criteria tells us or means, and whether this can be combined with a more personalised needs-led approach which considers the unique circumstances and experience of each child and family. Alvarez and Reid warn against the confusion between treatment and cure (1999, p. 16), as here, promoting the view that a change or reduction in symptoms should not be synonymous with a reduction in support. Some studies do recognise the view that diagnosis is not an endgame, although fewer advocate that diagnosis can be considered as a dynamic factor, rather than something which is fixed.

In a later study, Rhode and Grayson (2021) present an observationally and psychoanalytically informed parent-toddler intervention for young children at risk of ASD. They found that of the 8 children in the study, a significantly lower number were later diagnosed with autism than the CHAT would predict, suggesting that a larger study is necessary.

The 8 families were offered a modified version of Bick's infant observation method. The study aimed to make links between the child and their family, to support the parents by drawing attention to the child's aptitudes which they may not have recognised previously and to engage the child, noticing with the family what helps with this and what seems to prevent it: "what does not get noticed cannot get built on" (2021, p. 6).

Rhode and Grayson conclude by emphasising the intervention's key features of parental involvement, clinician's sharing of the family's emotional experience, centrality of meaning, support for the parents and promotion of receptive behaviours. (2021, p. 13).

2.5 Conclusion

Overall, the literature reviewed here suggests that psychoanalytic approaches can complement neurobiological formulations regarding recognition and aetiology of autism (Singletary, 2015). The literature highlights that need for the centrality of the caregiver-child relationship throughout the diagnostic process and also when considering post-diagnostic support. (Jacobs, Steyaert, Dierickx, Hens, 2019). The literature evidences the benefits of a therapeutic observational approach and what can be offered by the application of psychoanalytic thinking. Also, it evidences that offering containment to parents both in terms of post-diagnostic intervention and through dialogue throughout the assessment processes enables development in parental reflective functioning and can result in greater parental resolve regarding the outcomes of their child’s assessment, and increased confidence in feeling that they are able to meet their child’s needs moving forwards. (Reed, Giles, White and Osborne, 2019). However, I did not find any literature that evaluated WMP or other therapeutic interventions offered concurrently with diagnostic assessment. I hope that this project will complement Koenig and colleagues’ study (in publication) in beginning to explore parents’ experience of WMP and that it will add to further discussion regarding the ways in which WMP can be used. This study not only expands on research underway with families of children with developmental delay, but also attends more specifically to the parents’ lived experience: of the assessment process itself, their parenting of a child with social communication difficulties and of the offer and undertaking of WMP as a possible component of their assessment experience at this particular time in their child’s life.

3 Methodology

In this chapter, I explain the background and context for the study and the rationale for the chosen methodology employed in the study. I then outline the study design and process of recruitment and suggest reasons that families may have had which motivated some to take part and others to feel more reticent, or to withdraw after expressing initial interest. I describe the place of the study within the context of my service, but also within its epistemological and ontological positions.

3.1 Aim

My initial discussions with colleagues in my team concerned my interest in how psychoanalytic psychotherapy can help young children who have autism or have no unifying diagnosis, but have presenting difficulties with separating, acknowledging and navigating relationships with others. This led to a conversation about the ways in which the current climate within the NHS and wider services can privilege diagnostic assessment over a more holistic observation and analysis of a child, their needs and presentation. My colleagues described, anecdotally, the ways in which they have encountered families' disappointment at not receiving a unifying diagnosis, as though explanation of their child's difficulties (and at times access to support) are being deliberately withheld. Others described the relief that can be felt when a diagnosis is given – as though it is an absolution from blame. In both cases, it seemed as though the receipt (or not) of a child's diagnosis was experienced as something that is fixed, rather than dynamic, with limited space for reflection with a clinician about what a child's social communication profile, regardless of label, may mean to them.

The debate around the merits and disadvantages of diagnosis is ongoing. I have explored my position regarding diagnosis and diagnostic services and have concluded that from my experience, it is generally helpful to think of a diagnosis as a description of the child’s needs at any point in time and that as with all children, descriptions may grow and adapt as they develop their identity. Throughout this project, I have been mindful of this position. I have regularly checked my assumptions formed by my own experiences of working with autistic children and their families alongside my understanding and analysis of the material.

Initially, I was interested in exploring whether the offer of WMP alongside diagnostic assessment may enable a more needs-based approach, and what it may illuminate in terms of the experience of the child/family during the assessment process. I was also keen to explore the impact, on a family’s experience of an MDAT assessment, of seeing more of the whole child through play.

Additionally, I was mindful about the current reality of long waiting lists and the time that the diagnostic journey can take, particularly post-pandemic, and wondered about the impact of this on the experience of assessment when it finally arrives: how might a wait encourage or discourage investment in the process? Might it engender feelings of stagnation or abandonment? Might it foster anxiety about a child’s deteriorating profile, or perhaps encourage procrastination in thinking about possible painful things, or perhaps denial?

In addition to this, I was interested in how this might both inform and be informed by ongoing relationships with professionals and services. Cunningham and Davis (1985) identify three models by which parents of children with disabilities may engage in interventions offered by service provider. The first they called the “Expert”

Model, which exemplifies practice in which the professional(s) take the lead role in decisions about appropriate support and pathways and the parent is the passive recipient. The second is the “transplant model” in which professionals “transplant” skills and expertise to the parent, which is still not fully collaborative as the parent is not in control. As well as perhaps placing undue pressure on parents, Cunningham and Davis warn

> This model could promote unhelpful emphasis on the parents as having to absorb ‘teacher skills’ instead of communicating with their child in a more natural manner. (1985, p. 50).

The third is the” Consumer” Model, which is based on the assumption that parents have considerable knowledge which should be shared and offers equal status in the relationship with professionals. My view is that WMP is conducive with this model as clinician and parent work together to explore the relationship and attachments between parent and child, rather than offering pre-planned strategies or assuming an expert position.

3.2 Research questions

My aim was to arrive at research questions which focussed on the parents’ experience of both WMP and the diagnostic process concurrently as I am interested in exploring the interplay between the two and the emotional complexity that is inevitably aroused when families are faced with the question of whether there is something “wrong” with their child. I hoped to learn about how parents make sense of their situations, relationship with their child and the experience of taking place in WMP within this context.

At the outset, my interest lay in the following areas:

i) How do parents/carers of under-5s who are presenting with possible communication difficulties find the experience of WMP? Does it contribute towards building confidence in understanding and supporting their child?

ii) What is the experience of having a professional to talk to about their child's play like? Is it helpful alongside other types of conversations within the assessment process?

iii) In what ways do families experience taking part in WMP? What is the impact on the family's lived experience and thoughts about how their child experiences their disability?

iv) What might the experiences of parents contribute to supporting the establishment of WMP as an intervention within the routine practice of the MDAT?

These initial areas for exploration were distilled into **two key research questions:**

1) What are the experiences of parents with an under-5s child who is presenting with possible communication difficulties who is undergoing an assessment process?

2) What are parents' experiences of undertaking WMP alongside the assessment process?

3.3 Clinical Setting

This project was undertaken within the multi-disciplinary assessment team (MDAT) of the wider integrated services for children with disabilities within the London Borough in which I work. They offer multi-disciplinary assessment and diagnostic work for under-5s presenting with complex needs and possible developmental difficulties. The team is in part comprised of CAMHS clinicians who work across both services.

There are two clinical assessment pathways for children with developmental disabilities who meet with the MDAT depending on whether their needs pertain to social communication difficulties or possible physical and intellectual disabilities. The limitations of this study in terms of length and scope necessitated that I chose to focus on one pathway only, in order that the interviewees in the sample group would have been offered the same experience. For the purposes of this study, therefore, I concentrated on families whose children were being assessed for social communication difficulties and for whom diagnoses of Autism Spectrum Conditions or other Social Communication disorders were likely to be considered.

The procedure of diagnostic assessment across different services varies widely. That which is outlined below is particular to the service in which I work.

The assessment process for possible social and communication difficulties within the MDAT is structured around three meetings. The first of these, the initial assessment meeting, comes at the end of a long wait for families and their children, as prohibitive waiting times can mean that as a much as a year has lapsed between referral and first meeting. It usually lasts an hour, and families are met by two clinicians who gather information about the family's history, their concerns and current situation and thoughts about their child. The child is invited to play with one clinician and offered some toys, which forms the basis of the clinician's observations of the child. Then follows a six-week period, in which other reports are requested (such as school observations, occupational and speech and language therapy) during which the family are offered the contact details of the team, but no further formal meeting is scheduled. At the end of this, two meetings happen, usually on the same day. The first is the Diagnostic Formulation meeting, in which the team meet without the family to discuss the findings and to view these rigorously in the context of the DSM-V guidance for diagnosis. The second is the Assessment Feedback Meeting, during which the thoughts and findings of the team are shared with the family, who are then offered follow up support in the form of group workshops to think about their child's diagnosis, if the assessment process indicated this. The team is which I work is one of the few in which child psychotherapists are integrated into the assessing team: interestingly, NICE guidelines do not stipulate that this should be the case.

My study design proposed that WMP sessions should take place in the window between the initial assessment meeting, during the six-week interlude, and again two weeks after the Assessment Feedback meeting.

3.4 Why IPA?

Interpretative Phenomenological Analysis (IPA) is my chosen methodology for this project as my focus is the lived experience (Smith, Flowers and Larkin, 2009) of the participants: I am interested in the ways in which parents make sense of the experience of the assessment of their child's presentation and what, if anything, their involvement in a psychoanalytically informed therapeutic component may add to their perceptions of this, and their aspirations moving forwards. I explore below the rationale for selecting this approach.

In their book *Doing Qualitative Research Differently* (2000), Holloway and Jefferson highlight the assumption to which they feel that some researchers fall prey: that participants are "telling it like it is" (2002, p. 2) They say

> .. treating people's own accounts as unproblematic flies in the face of what is known about people's less clear-cut, more confused and contradictory relationships to knowing and telling about themselves. (2000, p. 3)

They continue with the helpful reminder that in everyday conversation, rather than assuming that another's account can be trusted wholesale, one takes a more questioning, interpretative position. They remind us that research is no different in this regard and make a plea for the place of "everyday subtlety into the research process." (2000, p. 3) They state that "if we wish to do justice to the complexity of our subjects an interpretative approach is unavoidable" (2000, p. 3).

They emphasise that the same, open approach must be applied to the "researcher as well as the researched". (2000, p. 3). It felt to me that a methodology that is predicated on the co-construction of data between researcher and participant, as well as one which encourages active engagement with the experience of being interviewed, as well as of the chosen subject discussed seemed particularly appropriate to this project. My interviews, which included questions about experience of the service, were to be held with a clinician, in the clinic that is the subject of the discussion. This adds an extra dimension to the hermeneutic cycle. (Larkin and Thompson, 2009). As Larkin and Thompson state,

> phenomenological inquiry is a *situated* enterprise… while phenomenology might be descriptive in its inclination, it can only ever be interpretative in its implementation. (2009, p. 102)

In addition to this, I felt that Larkin, Watts, and Clifford's' description of IPA as a stance rather than a distinct method (2006, p. 104) offered an opportunity for a degree of freedom and creativity in approaching the data in a dynamic way. They outline that the objectives of IPA are to

- Try to understand the participants' world in order to describe what it is like
- Then develop a more interpretative analysis which positions the above 'description' in relation to wider social, cultural, theoretical context.

The positioning of one's analysis in its wider context seemed particularly pertinent for this study and the ways in which the findings may be used to add to the services' understanding of diagnostic processes within the climate of the clinic, and our wider social and cultural contexts.

3.5 IPA and psychoanalysis

Epistemologically, both psychoanalysis and IPA share a focus on a person's relatedness to the world (Larkin & Thompson, 2011, p. 102). Both are studies of being and as such are concerned with meaning rather than process (Larkin & Thompson, 2011, p.102) and focus on the particular rather than the general.

This project is rooted in the psychoanalytic principles of child psychotherapy: the centrality of an observational approach; the value of play as unconscious communication; the examining of the past within the here and now of the transference situation.

As such, there are a number of epistemological assumptions that I made which I feel it is important to acknowledge:

i) We all operate consciously and unconsciously
ii) One’s internal world is separate from and different to one’s external world; complex interplay exists between them
iii) Research is by definition concerned with Intersubjectivity and shared meaning making (Larkin & Thompson, 2009)

Holloway and Jefferson (2000) helpfully illustrate the ways in which they feel that all research subjects are

…meaning-making and defended subjects who:

- May not hear the question through the same meaning-frame as that of the interviewer
- Are invested in particular positions in discourses to protect vulnerable aspects of self
- May not know why they experience or feel things in the way that they do
- Are motivated, largely unconsciously, to disguise the meaning of at least some of their feelings and actions (2000, p. 26)

> Throughout the data collection process, I kept a reflective journal to document my observations of my countertransference and thoughts about the transference within the interview situation as well as those that arose in terms of my own responses, prejudices and position throughout the interviews.

3.6 Study design

The outline of the study design is as follows:

Participants were identified from the existing waiting list for diagnostic assessment. There were no exclusion criteria as it was my aim that the participants should be, as far as is practicable, an authentic representation of the community in which we work. Families at the top of the list were contacted systematically and invited to take part in WMP. WMP was not offered to families who were not going to take part in the study. It was made to clear to prospective participants that the offer of WMP was additional to the assessment process and that taking part in the study, if they decided to consent to taking part, would have no bearing on the outcome of their child's assessment.

A colleague who did not have any other involvement in the project conducted the initial introductory telephone call to ascertain whether they would like to take part.

After initial recruitment was confirmed, the families were invited to their first introductory meeting with their WMP clinician in which informed consent for participation in the study was taken. In order to do this, the WMP clinician went through the participant information sheet (which the families had also been given in advance), answered questions about the study and talked through the consent form. When the parents felt they were happy to proceed, they were invited to sign the consent form. Following this I conducted the first, pre-WMP interview. We held these meetings immediately after one another to avoid the inconvenience for the family of multiple journeys to the clinic. These took place before the Initial Assessment meeting with the MDAT team.

Following the Initial Assessment meeting with MDAT, between 2 and 4 WMP sessions with a qualified child psychotherapist were offered, depending on the family's availability and the timings of the child’s assessment. The diagnostic feedback meeting was then held with the MDAT team. One or two more WMP sessions were then offered, depending on how many had taken place before the Initial Assessment meeting. On completion of WMP, families met with me for the second research interview. Participants were invited to take part in semi-structured, in-depth interviews (as outlined above) in order to have the opportunity to speak freely and in detail about their experiences.

I hoped that, by offering these interviews at two time-points, and possibly alongside their reflections in the WMP diaries, the data collected would be rich and that participants would feel that they have been given sufficient opportunity to speak thoroughly about their experience and that their thoughts, concerns and reflections would be received with interest and serious consideration. The interviews were transcribed and then analysed by me. IPA allows for freedom and creativity in the analysis of data collected: it is an iterative and inductive cycle (Smith, Flowers and Larkin, 2009, p. 79) although the focus of the analysis remains the specificity of the participants’ experiences.

The sample size was small as is expected for IPA and so its generalisability and replicability may be called in to question. It is my hope that the above literature review and the discussion of the analysis and findings below will place this study within a wider context of research and thinking and invite readers to consider further transferability and contextualisation as a result. As Smith Flowers and Larkin state, “the effectiveness of the IPA study is judged by the light it sheds within this broader context. “(2009, p. 51)

3.7 Recruitment

In total, the first 13 families at the top of the MDAT assessment waiting list were approached. 9 initially said that they were keen; 5 of whom changed their minds before attending the initial introductory meeting. In total, 4 families were recruited to take part in the study. Two of these attended the introductory session and first interview but dropped out before commencing WMP; the remaining 2 completed both interviews and the full offer of WMP sessions. Therefore, the data collected comprised of 3 pre-WMP interviews and 2 post-WMP interviews.

3.8 – Data analysis

Data analysis in IPA is flexible in that there is no single prescribed approach to beginning to explore the data. (Smith, Flowers and Larkin, 2009). It is iterative and inductive, meaning that the process for arriving at an exploration of what matters to participants and what this may mean to them is one of revisiting – “cycling and recycling” (Smith, Flowers, and Larkin.2009, p.105) strategies for approaching and interacting with the transcribed data.

IPA does not test hypotheses; therefore, it was important that I reflect on my own assumptions, perceptions and preconceptions as they became apparent to me throughout the process of data analysis. I aimed to capture these both in my reflexive journal (Smith et al., 2009) and in the first stage of data analysis – as outlined below. I used my reflexive journal as a way to maintain awareness of my assumptions and to ensure that I wasn't unconsciously looking for experiences that supported my position. I referred to this throughout the data analysis and it proved a helpful tool in focusing an understanding of my interpretive analysis of the material generated.

I took each transcript in turn and conducted the following steps: (Smith & Nizza, 2022).

i) **Free coding:** I annotated a clean transcript with my own initial thoughts, recollections of my counter transference then and now in the revisiting of the material, reflections, initial ideas, psychoanalytic concepts that appeared pertinent. This I repeated twice – once whilst listening to the recorded interview, the second time revisiting and adding to my comments. I then recorded my observations about my own responses in my reflexive journal

ii) **Line-by-line analysis – initial coding and exploratory comments:** I placed the transcript in the middle column of a table and began line by line analysis. I used the left-hand column to record codes, and the right for explanatory comments. Peer supervision was helpful at this stage to identify the correlation between my free coding and explanatory comments; in particular my unconscious assumptions that I had not identified in the free coding stage. It was also helpful in supporting me to reflect on the then-and-there experience of the interview and how this may have impacted the data.

iii) **Line-by-line analysis: developing possible interpretations:** I returned to the initial coding and added to this column (using different colours to differentiate between the different stages of the analysis). Under the codes I had already noted, I began to identify possible interpretations, what Larkin and Thompson refer to as “phenomenological coding” (2011, p. 106). I then added a further column to the right of the transcript to record the dentification of “objects of concern” to the participant (i.e., things that matter such as events, values, relationships etc); and then “experiential claims” (indicating the meaning of these objects of concern) that were suggested by these possible interpretations.

iv) **Preliminary organisation of possible themes:** When this coding was completed for one transcript, I clustered each code regarding an object of concern/its meaning under broad emerging themes in order that these could be more easily compared across each participants’ data.

v) **Establishing a dialogue: between me, my psychoanalytic knowledge and the data:** Smith et al (2009, p. 84-88) suggest categorising descriptive, linguistic and conceptual comments when examining initial data. I then returned to my initial comments to look at the balance between these. These I organised in a separate table to then be compiled with the preliminary themes to form a map for each transcript.

vi) **Arriving at themes:** Having familiarised myself thoroughly with the minutiae of the data, I then compiled these to form one table which outlined the objects of meaning and experiential claims across each complete data set for both pre-WMP and post-WMP interviews. Adopting a more interpretative stance, I used this to arrive at themes and sub themes, which I then complemented with quotations from the source data and moved and grouped in different ways until I felt that they were an accurate representation of the content of each group. Each theme is addressed in my findings chapter below.

3.9 Ethical considerations and anonymity

I gained full TREC approval for this study (see appendix). Participants were aware that they could withdraw at any time (two participants decided to do this).

I have removed all identifying information to maintain anonymity, although as this is such a small sample group it is difficult to disguise the participants completely.

3.10 Participants

Parents of four children took part. Each parent has been given a pseudonym:

Joanne

Alice

Sabrina, Mother, and Jay, Father

Helena

3.11 Interview Questions

The aim of the pre-WMP interview was to explore the parents' experience of their child and his/her play at the outset of assessment; to hear about their feelings towards professionals in general and services they may have had experience of previously as well as the upcoming diagnostic process. I was interested also in the language that parents may use and the aspects of their/their child’s experience which they chose to describe and the ways in which this would indicate their unconscious feelings about their relationships and situations. Initially, I had planned to include the WMP Goal-based measure in these interviews. On reflection, I decided that it was better that that part of the work was conducted by the WMP practitioner, as is usual in the process of offering the intervention. This ensured that the interviews with me were kept separate and the focus would remain on the experience of the process, rather than the measuring of its success.

Pre-intervention interview questions:

1) In your own words, please can you tell me about your child … *possible prompt: can you give me three words to describe your child and tell me why you chose them*
2) What is the difference between a good day and a bad day in your family?
3) Can you tell me about something/someone who is important to your child?
4) How did the referral to MDAT come about? *possible prompt: Can you tell me about your experiences of coming to this clinic before?*
5) Does your child play? If so, can you tell me about some of the things they do?
6) Can you tell me about a recent time when you and your child were together?
7) Is there anything that might make it difficult for you/your child to do Watch Me Play?

The post-intervention questions were largely the same as the pre-intervention questions, as I was interested to see whether answers had changed and what this might suggest about how the experience of WMP had impacted on the participants' experiences of parenting their child:

Post intervention interview questions:

1) In your own words, can you tell me about your child now… *possible prompt: which three words might you use now to describe your child and why?*
2) Can you talk about your experience of the beginning/middle/end of the intervention? *Possible prompts: what has doing WMP been like for you? What has it been like for your child?*
3) Did anything surprise you?
4) Did anything change for your child or for you, in ways that you didn't expect?
5) Were there any challenges with doing WMP with your child – if yes, what were they?
6) Have you noticed any changes in the way your child plays – by themselves or with others?
7) How will you remember the experience?
8) How do you think your child will remember the experience?

At the end of the interview, I also offered an opportunity for the participant to say anything else that they thought it might be helpful/important for me to know about their experience.

Overall, data was collected from the following interviews:

- Joanne: attended pre-WMP interview and then withdrew from the study

- Alice: attended pre-WMP interview and then withdrew from the study
- Helena: attended both pre and post WMP interviews
- Sabrina: attended the pre-WMP interview
- Sabrina’s husband, Jay: attended the post-WMP interview

4 Findings

This chapter presents the findings from the pre- WMP and post- WMP interviews. I present the themes and sub themes that emerged from my analysis of both data sets, describing each theme in turn. These I support with quotations from the data. I have included a table of themes in order to illustrate the correlation between that which emerged from both data sets.

I have organised the themes so that they relate to the two research questions established in my methodology. The first two themes relate to the first research question:

What are the experiences of parents with an under-5s child who is presenting with possible communication difficulties who is undergoing an assessment process?

The last theme relates to the second research question:

What are parents' experiences of undertaking WMP alongside the assessment process?

4.1 Themes

Three predominant themes emerged from the analysis of the pre-WMP and post-WMP data. These are presented in the table below:

Research question	*What are the experiences of parents with an under-5s child who is presenting with possible communication difficulties who is undergoing an assessment process?*		*What are parents' experiences of undertaking WMP alongside the assessment process?*
Theme	**It's a battle**	**Things don't join up**	**Seeing things in a new way**
Subthemes	Experiences can feel extreme Experiences can feel painful or relentless I can feel controlled and helpless	My child can feel far away from me My child is on their own My child and I experience the same distress Families and services feel disconnected Participant and researcher feel disconnected	Noticing differences Feeling more connected

I examine each theme and its sub themes below. The frequency with which each participant contributed to the theme is illustrated in a table at the beginning of each section.

4.1.1 It’s a battle

Participant	**Number of references to theme**	**Page/line numbers in transcript**
Joanne	**15**	1/26, 1/33, 1/39, 1/40, 2/44, 2/45, 2/81, 2/95, 2/100, 4/163, 8/305, 9/347, 10/376, 10/409, 11/417
Alice	**6**	1/7, 1/9, 1/18, 2/52, 4/100, 4/117
Sabrina	**6**	2/55, 2/58, 2/61, 5/150, 6/164
Jay	**0**	-
Helena (pre WMP)	**10**	1/11, 1/23, 2/36, 2/52, 2/57, 3/103, 4/108, 4/126, 5/162, 5/164,
Helena (post WMP)	**3**	2/43, 2/67, 2/77

This theme captures the feelings of extremity that participants described in their experiences of their children, whether this was explosive or hyperactive behaviour for some, or persistent repetitiveness. These experiences could feel both enjoyable and tiring as well as difficult to describe or understand. There was also a sense of how, at times, the experience of parenting could be painful and evoke strong feelings of worry, and even of feeling out of control, either as a result of the child’s behaviours or in the struggle to manage and understand difficult and painful situations. Three subthemes emerged from this overarching theme:

Experiences can feel extreme

Joanne, Alice and Helena described how their children's volatility could be experienced by others as disproportionate at times. For the children, and sometimes for the parents too, these extreme reactions could feel highly stressful for children and adults, and at times, catastrophic. The experience of each child’s aggression and distress erupting in these volatile and explosive ways was accompanied by participants' description of the ongoing impact that this could have on them and on their wider families. This impact could feel painful and at times interminable to them, as well as distressing and anxiety provoking. They talked about how these experiences could also evoke confusion and distress for their children, as it was difficult to help them to understand when a difficult experience was over and to help them to differentiate between "then" and "now."

Joanne described her child's response to small mishaps, such as a minor injury: "*her reaction to these things is, are, a million trillion times more than they should be" (1/26).* The feeling that difficulty is experienced as extreme and unpredictable seems to be more related to the child than the parent in this example. Joanne's implied response is one of both frustration and shock as well as accompanying anxiety. Similarly, she described her daughter remembering these mishaps as though they were occurring in the moment:

> *she kind of recalls things that have happened, and her reaction to them even though it isn't there anymore, is just as bad as when it first happened… it's happening again every time... and it's really difficult to explain. (1/33-37).*

The difficulty in helping her child not to feel overwhelmed and upset all over again, whilst balancing her own anxiety in response to her child's distress and feeling at a loss as to how to help her to understand was conveyed to me as both debilitating and painful.

The unpredictability of such incidences was evident in Joanne's words "*every day's an experience!"* (9/347). Whilst humorous, I felt this also intimated how it could be hard work pre-empting, responding and containing these possible and unpredictable moments of high levels of distress and anxiety.

This was also conveyed later in the interview, when Joanne described her experience towards the end of the initial assessment interview when trying to help her child manage the experience, which was becoming overwhelming: "*it was like a bomb hit." (10/409)* The destructive quality of this phrase illustrated the need to convey to me, the interviewer, just how explosive things could feel if a situation was felt to be out of control. When reflecting on this moment, Joanne wondered about possible actions she could have taken in response to her child's behaviour at that time but added *"in the chaos... you don't think of that because you're not really thinking"* (11/417). The powerful impact of such moments of "chaos" renders thought impossible.

Similarly, Alice described her child, albeit affectionately, as *"a little hurricane" (1/7),* also evoking feelings of unpredictability and a sense of terror of possible destruction. Alice qualified this comparison with further description of her child's volatility, explaining that he *"throws himself on the floor, he is shouting, he's screaming..." (2/52).* Her description of a "little hurricane" could be considered oxymoronic: both capturing the intensity of his rage and distress, but also how vulnerable and small he is. She perhaps experiences incongruity between the enormity of the impact of his emotional response and the reason for his distress.

Helena described her daughter in a similar way. She said that her child can be "a *little bit aggressive"* (1/20), but her experience of this suggested that at times this could feel more of an attack: "*... shouting, like mostly towards me. She'll pull my hair, bite me, hit me sometimes". (1/23).* She continued in more pragmatic terms, explaining that *“so normally if she’s having a stressful day, I’ll just taker her out, erm, go to the park or something...”* (1/28). This suggested how routine these experiences can feel for Helena, that the attack is almost minimised at times. However, she spoke differently about her daughter’s newly acquired language.: “*she talks loads now, to the point that it’s too much!” (2/52)* continuing that *“even if there’s five minutes quiet, she just has to fill it.” (2/57).* Extremity is experienced here in terms of verbal onslaught: her daughter is not distressed at these times but Helena herself feels overwhelmed and exhausted by her demands.

Experiences can feel painful or relentless

The second sub theme captures the experience of painful experiences that could have a relentless quality. All participants’ responses included references to experiences of this kind; particularly in terms of their children’s repetitive behaviours or play, which could feel impenetrable and incur feelings of bemusement and dismay as well as anxiety.

Alice used repetition to describe the relentless quality of her son’s activity: *“he can throw his toys on the floor, then go and do something else, then come back and play, and then go and do something else”* (1/9) which implied both her bemusement as his persistence but also perhaps her own exhaustion and frustration.

Joanne and Helena also used repetition to emphasise their experiences of their children’s seemingly relentless behaviour, both at times of distress but also at times when each child was enjoying themselves.

Joanne described how at points when her child is upset “*the episodes last for twenty, thirty, minutes of screaming and crying and whingeing and whining and it seems to* *go on forever." (1/26).* This implied that she feels as though she is unable to make things better; nothing she does makes any difference or helps to assuage her child's discontent. The list of the different complaints and communications from her child illustrates her exasperation, which is accompanied by both a sense of vivid intensity and despair as to what to do to help.

Experiences of relentlessness were also apparent in descriptions of more positive interaction. Joanne said of her child's behaviour *"it's very compulsive and repetitive" (1/40),* explaining that this can include difficult moments but also activities that her child likes doing: "*she wants to do all these things she enjoys, and she wants to do them every day."* (1/41) The feeling of exhaustion that accompanies her desire for her daughter to enjoy herself was clear.

Helena listed the activities that her daughter enjoys: "*running, jumping shouting, singing dancing. Wiggling, playing... everything! Honestly, she's minute she gets up, minute she goes to bed. Nonstop!"* The feeling of exhaustion seemed particularly present for me in her use of the word "honestly"; it was as though the never-ending activity had to be experienced to be believed.

The feeling of helplessness at seemingly never-ending distress was also present in Helena's response to the question about what makes a good/bad day: *"she doesn't' like noise, she doesn't like smell, she doesn't like eating, she doesn't really like sleeping... erm yeah. She doesn't like anything really! She just likes… dunno…" (1/23)*. Here, Helena also uses a list to communicate her struggle to help her child to settle in which the emphasis is on the things that her daughter "doesn't like" which feels interminable; also conveying a sense of despair at not being able to find a solution. Helena's feeling of being unable to help her child to calm, is particularly poignant in her listing of all the things that don't seem to help.

The painful intensity of some of these experiences, vividly conveyed above, could also be noted in Sabrina's description of her child, such as in "*he used to talk; now he doesn't talk" (*2/55). Her use of repetition demonstrates her anxiety about the change that she has perceived in her child as he has got older, and conveyed a sense of dismay at what she perceived was a loss of development. She returned to this worry frequently throughout the interview and her experience of his difficulties with speech seemed to oscillate between concern "*he understands everything, but he can't explain"* (6/164) to feeling more persecuted "*he won't answer but he will come"* (2/58). There was also a strong sense of her own relentless anxiety that her parenting had somehow caused this developmental delay in her list of previous milestones that she felt he had reached and then lost, such as: "*he used to look up at the TV"* (1/15); "*he used to smile"* (1/7; 1/23; 1/27) "*He used to call Mummy and Daddy*" (1/13); "*he used to pay with toys, he used to laugh*" (1/25)

I can feel controlled and helpless

Feelings of helplessness and being controlled were described by Helena, Sabrina and Alice. In reference to her daughter's play, Helena described how *"she's quite controlling, she only really likes me watching. She doesn't really like me getting involved and if I do get involved it can be quite stressful for her, so it's only if she lets me get involved." (5/164).* This suggests a reticence to join her daughter in her play in case of escalating conflict or stress, which then, perhaps, would not be able to be contained.

Sabrina talked about how her child *“hears me ok, but he doesn’t answer” (2/61).* Both imply that at times the parents experienced their children as controlling of their environments.

When asked how she would describe her child, Alice replied, *“I think I’ve run out of words for him”,* perhaps implying despondency or loss of her own agency.

The experience of feeling controlled and helpless was still prevalent in the post-WMP data. Helena described how some parts of WMP were challenging: “*You can’t have a specific box*

because she’d get bored with that... and I’m not going to have an argument with someone about toys!” (2/43)

For Joanne, the battle was also outside of the relationship with her child; she described her experience of the process of getting help and support in similar terms: “*I had to get in early and I had to fight a lot and it’s been a battle to get where we are”. (8/305)*

4.1.2 Things don’t join up

Participant	**Number of references to theme**	**Page/line numbers in transcript**
Joanne	**24**	2/52, 3/87, 3/94, 3/110, 4/151, 4/164, 5/175, 5/196, 5/201, 6/207, 6/215, 6/231, 7/264, 7,273, 7/278, 8/287, 8/295, 8/312, 8/321, 9/331, 9/349, 9/362, 9/372, 10/391
Alice	**9**	1/15, 1/17, 1/18, 2/38, 2/49, 2/59, 2/65, 3/68, 3/76
Sabrina	**11**	2/44, 2/58, 2/60, 3/80, 3/85, 4/96, 4/101, 4110, 4/118, 5/134, 6/176
Jay	**2**	1/30, 2/40
Helena (pre WMP)	**4**	1/19, 2/62, 3/71, 4/131
Helena (post WMP)	**1**	1/19

The second theme reflects feelings of disconnection: the subthemes include feelings of distance between parent and child and also experiences of undifferentiation between parent and child. In both these situations a sense of relationship, of coming together, could seem absent. For some participants, the sense of helplessness covered in the first theme was accompanied by feelings of confusion about their child’s behaviour or play, while others felt that communication with their child was difficult.

This was at times evident in the description of the child’s interactions with others (e.g., peers and wider family members), as well as in the parents’ descriptions of how it can be difficult to make connections between their child's behaviour and their needs and wishes. There was also a strong sense of disconnection between families and professionals, and feelings of confusion and being lost in the challenge of navigating clinical pathways and processes. I also experienced moments of feeling disconnected during the interviews. At times I felt confused while listening to participants and some questions which I had thought would be straightforward turned out not to be.

Five subthemes emerged from this theme. These were more present for Joanne and Sabrina than for Alice and Helena.

My child can feel far away from me

This sub theme captures experiences of distance between parent and child. For Alice, the distance was implied in the way that she used opposite terms to describe her son: he could be at times, "*perfect" (*2/38), whereas at other times he *"throws himself on the floor, shouting screaming." (1/52).* The polarity here also supported the feeling of extremity which is explored in the theme above. Similarly, her phrase *"I think I've run out of words for him now, it doesn't come to my mind*" (1/ 18), also explored above, conjures the impression that her experience of her child can be elusive. It is hard for her to convey what he is like (particularly in English when it is not her first language, perhaps).

Helena also used opposites to describe what her daughter is like: "*even though she's hyper, she's really chilled"* (1/19). This also suggested feelings of ambiguity, or contradictory parallel experiences of her child, again implying distance in that it is hard to arrive at a description that feels as though it fits.

The sub theme "My child can feel far away from me" felt particularly present for Sabrina and Joanne, who were both worried about their children's delayed language development and difficulties with communication. This sense of loss, or distance, was also prevalent for Sabrina, who felt that her child's development had stalled following a trajectory that at first seemed to be neurotypical. Sabrina explained that her child "*used to smile. He was a good child; he didn't make any hassle" (6/7)* communicating anxiety that something had happened which had led to a change in his presentation. or perhaps, closer to the subtheme of My child can feel far away from me, the sense that the good child who used to smile is lost or gone.

Sabrina spoke much about her worry about her child's repetitive play and her concern that he doesn't respond to her with words:

... that's one thing that I'm worried about: that he used to talk, and say mum I'm coming, now it's like he hears me call, he doesn't say I'm coming, but he will come. So, he won't answer but he will come. (2/59)

She contrasted this concern with her observation that he is able to meet his own needs without needing to ask: "*He can go and get his shoes, he can read the label, but he won't say, he will just go and get it"* (4/118).

The emphasis that she placed on this communicated a mixture of both advocacy for his capabilities, but also feelings of being rejected or dismissed in some way. The distance that she experiences is perhaps both hurtful and hard to fathom.

Joanne also said that her child's lack of verbal development was a concern for her. She commented that at times when her daughter is upset *"she can't tell me, she can't verbalise, erm, how she's feeling, or why she's feeling like that or if she's tired. Erm... so the lack of language is quite tough sometimes" (3/94).* The impression here is that her daughter, when distressed, is hard to reach: it is difficult for Joanne to feel confident that she is attuned to her child at these times. Joanne further explored the experience of her child’s verbal development, saying that *“sometimes, randomly, she’ll say something in context, but it’s so random, you’re not really sure if it is in context, or it’s just that time”* (3/10). It is hard to be sure whether her child’s communication is intentional, or coincidental, and whether progress is definitely being made.

A sense of distance was also present in Joanne’s acknowledgement of the different developmental pace when comparing her child to others: “*she can communicate, just not at the same level as peers of the same age, I guess.”* (6/231). This was also suggested in her comment that “i*t’s not what you expect when you have a child”* (10/393). The experience of acclimatising to a child with additional needs was unexpected, and perhaps daunting, and painful.

The sense of distance conjured through feelings of confusion was also evident in Joanne’s observations of play. Joanne said, *“I think that she can play, and she does play, but a lot of times, a lot of the time I feel like its empty”* (5/196). It is hard to discern meaning, or intent, in what her daughter is doing. She explained further*: “I don’t really know what she does... it’s like she potters around, she moves between the lounge and the kitchen, stops and then does a little bit of something, and then she’s back again. So, I don’t know if a lot of time gets lost with her just faffing.”* (5/201)

It is hard to recognise this “pottering” as having purpose or discernible pleasure, or to identify it as play. Perhaps because her behaviour is not recognisably a role-play, or a specific game or activity with common rules or features. Perhaps too, the impression that her child is in her own world may also have felt feel excluding, or the experience was that her child was hard to reach.

Play was an important element in all participants' everyday experience, but recognising when or what is play incurred interesting observations. All participants linked play with specifically with named toys or activities rather than the experience of recreation. Sabrina's description of her son's repetitive interest in buses conveyed feelings of frustration and concern, rather than curiosity *"If he is ill, he still plays with toys. The bus is his favourite." (3/85)*

My child is on their own

As above, play was described as both a solitary experience for the child and at times an isolating one for parents. At times parents felt excluded themselves by their child. Alice noted that her child's play was very much a solo activity: "*He can throw his toys on the floor... then go and so something else… then come back and play…. Then go and do something else…" (1/9).* This conveyed an impression that she feels that her child does not appear to need others to enjoy being with or do things together.

Sabrina spoke similarly about her son: "*he understands which are his toys, so if he sees other children breaking them, he just takes his away." (5/145).* This suggested that she felt that he would avoid communication with other children. Whilst Sabrina was perhaps on the one hand pleased with her child's sensible approach, there was also a sense of dismay in the thought that her child sees other children as something to be avoided and adopts a default position of dealing with things on his own.

The pre-intervention interview question about a recent time spent together prompted accounts of painful experiences, often at times when participants felt that their children were isolated or could not get involved in shared experiences with themselves or with other children. Joanne described poignantly the experience of observing her daughter in a group activity*: "... she was the only one that wasn't doing what the other children were doing… " (9/354).*

The experiences of feeling that their children can be excluded or excluding above was contrasted in the sub theme My child and I experience the same distress, which is explored below.

My child and I experience the same distress

This subtheme identifies how at times parents could feel that they were one with their child or felt isolated from others outside of the parent-child dyad. Joanne spoke movingly about how distressed she felt when observing her child in a group, as though she herself was being observed: *"As a parent, with all the other parents there, all their children are joining in… I couldn't watch anymore" (9/364).* She too felt worried about judgement and the subsequent painful humiliation that they both might have been subjected to.

Helena's description of her child's desire to be busy indicates that the constant feeling of being on-the-go was one too that she lived alongside her child: "*minute she gets up, minute she goes to bed. Non-stop!" (1/12)*

For Alice, the experience of a shared experience, inaccessible to others, was more present in her references to the way that other family members are unable to manage his behaviour: "*it's me that calms him down." (4/117).*

Families and services feel disconnected

There was a strong impression of disconnection in the relationships between families and services. Professionals were entirely referred to by discipline rather than by name (e.g., "Speech and Language Therapy") suggesting an experience of something impersonal, impenetrable and at times actively hostile. Joanne said that "*it was a negative experience for me" (7/2470,* conveying feelings of frustration and helplessness in comments such as *"a lot of it was wasted, I feel that a lot of time has been lost because nobody was doing anything." (7/276).*

The impact of waiting was mentioned by all participants, sometimes accompanied by feelings of resignation, such as in Helena's words *"They just said I was on the waiting list so there wasn't really anything I could do"* (3/72), and also confusion or disorientation:

> *I moved into the area, so the process was already started and then I changed my GP which I didn't know and so I had to start all over again*... *I don't know if they are going to send him to therapy or I don't know nothing else. I am waiting. (Alice, 3/68).*

This was compounded by the impact of the Coronavirus pandemic, which exacerbated the experience of services as inaccessible and obtuse. Alice said, "*I saw the paediatrician when they opened the doors" (3/76)* implying having felt shut out. Sabrina's description of the process of referral was similarly confused:

School sent me to the speech therapist. I came one time before the Pandemic, and she played with him. I'm not sure if it was here or somewhere else, but they said that they would send him for an assessment, but I don't know. (4/97).

The emotional impact of waiting for assessment or treatment was alluded to by Alice, who said “*It was hard because you’re getting yourself ready and then there’s a waiting list”. (2/65).* She used the word “hard” three times in reference to the initial phase of attempting to get help; suggesting struggle and anxious frustration which was perhaps difficult to name whilst in the company of a professional (i.e., me) inside an NHS building.

Joanne spoke more freely about feelings of anger and indignation about experiencing being dismissed by professionals:

> *.. there was nothing forthcoming. And I was asking, I asked can you refer me somewhere, can you refer me? She’ll have her two-year check. Two years! That’s two years! That’s a whole year away at this stage. (7/266).*

The incredulity in her use of repetition exemplifies her experience of being met with apparent disinterest and her feeling of being abandoned and not helped. Joanne expanded on this with concerns about how other families in similar situations might have managed:

> *It’s a long time because for me as her parent I noticed this stuff early so I got on it, I only noticed it early because I know... What about those families that don’t know? Those families that are first time parents and don’t know what to expect. A lot of families are in that situation and haven’t got a clue and that’s where children are being failed and they’re not being failed by their parents they’re being failed by the system. (8/295, 8/313).*

Participants and Researcher feel disconnected

Throughout the pre-WMP interviews, my countertransference varied in response to the discussions about family's experiences of services like my own. I felt acutely aware of the setting for the interviews – an NHS clinical room which also housed some medical equipment – and of my own position as an NHS employee. Joanne commented "*I don't like to speak negatively of services because I know how much you put in and how hard you work" (8/315):* the use of the pronoun "you" seemed to suggest that she, too, was very aware of my professional position.

Similarly, I wondered if at times during the interviews, I was felt to be abandoning and unhelpful, as in the following:

> *(pause)... is there any… like do you want to ask me about areas, because then it might kind of… because a lot of things... like... its normal for me now, I don't really see it as being different, I don't really have anything other than my nephews and being round a lot of other children to compare it to… (Joanne, 2/52)*

In the pre-WMP interview with Sabrina, the interpreter seemed to me to be in receipt of a projection of frustration, as she commented to me that *"Mum is going on about the bus". (3/85).* I noted also that Sabrina's demeanour – a sigh and shifting in her chair – suggested to me that she felt tired of answering what seemed to her to be the same question. I wondered to what extent my questions felt repetitive and pointless, much like her experience of her child's play.

The overall sense of disconnection felt less prevalent following the intervention. The theme seeing things in a new way captures this change.

4.1.3 Seeing things in a new way

Participant	**Number of references to theme**	**Page/line numbers in transcript**
Joanne	**2**	4/142, 6/212
Alice	**0**	-
Sabrina	**0**	-
Jay	**6**	1/12, 1/15, 1/22, 2/40, 2/71, 3/84
Helena (pre WMP)	**0**	-
Helena (post WMP)	**20**	1/9, 1/21, 1/29, 1/33, 1/35, 2/44, 2/53, 2/58, 2/64, 2/66, 2/70, 3/85, 3/100, 3/102, 4/124, 4/128, 4/143, 3/149, 5/155, 5/158

The final theme encapsulates some emerging sense of greater connectivity between parents and children and my impression that participants were able to speak more about enjoying time playing with their children. This was possibly as a result of taking part in the intervention and also having had the opportunity to reflect in the interviews with me. The participant who completed both parts of the study talked about finding WMP beneficial and responses implied greater nuance in understanding of her child’s communication. The responses of the second participant who completed the post-intervention interview also suggested that taking part had been beneficial, although as they did not complete the pre-intervention interview, it is unclear how much of a change can be attributed to their involvement in WMP.

A slightly stronger sense of context for both the parental-child relationship and the relationship with services was communicated by both participants. They both referred to the sessions within the context of coming to the building for other appointments and services. Both spoke of the children identifying the sessions with either the name of the clinician (“are we going to see… (name of clinician)”?) or the cartoon on the door of the therapy room (are we going to the blue dog room?). The room in which the WMP sessions took place gained particular significance, not dissimilar to that of the consulting room within psychoanalytic work. It provided useful containment for parent and child, and both participants referred to the difference in experience between coming to the clinic to play in comparison to play at home. Helena described how her experience had led her to believe that WMP could be a helpful component of the assessment pathway. She felt WMP had added an extra forum in which to think about her child’s development, and her own emotional responses to it. This suggested that she felt that a dialogue between parent and assessing clinicians could be reciprocal and helpful for both parties.

Post-intervention, Jay said that their child enjoyed the sessions, but this was contradicted by his comment that his child didn’t like the interruption to his preferred, repetitive activity: *“I think he enjoyed it… most of the time he didn’t like too much staying here or too much of contrast to what he was doing.” (1/15)*

Jay described his experience of WMP as a mixture of pleasure and obligation: “*although it was because of him, I have to come here all the time because of him, but I mean I enjoyed it though.” (1/22)*

His recollection of the child psychotherapist playing with his child in the WMP sessions linked play with clinical purpose: *“she was trying to help him, to give him some eye contact and to help his speech”. (1/12)*

These reflections indicated both felt that there was dialogue and shared experience with their WMP clinician, in contrast to the less personalised relationships with professionals implied in the pre-WMP data completed by Helena and Sabrina.

Taking part in WMP had offered an opportunity for both Jay and Helena to reflect more closely on their child's experience of play. The sessions provided space which meant that observation and developing an interest in their child playing was more possible; and subsequently for Helena, her anxiety diminished. Although both still described play as repetitive and at times still felt controlled by the child, the data suggested that for Helena, the experience of this was felt to be different: she responded more calmly and noted more variety in the play particular with choice and use of toys.

Helena noted that prior to the intervention, she had worried about how she can "*get stuck on one thing".* Post- intervention, she described feeling more comfortable with repetitiveness, instead *"just letting her have free time to do what she wants without getting interrupted." (1/29).* Whilst the sense of relentlessness is still present in these responses, they suggest that the painful anxiety experienced that she before has lessened slightly. Her child was playing in the same way, but her own feelings and attitude towards the play has changed.

The experience of play as controlling and repetitive also seemed to have shifted post-WMP and greater separateness between parent and child was noted. Helena commented on how it was easier to take an observer position rather than feeling pulled into feeling controlled: "*I get quite frustrated with her; it was nice to just let her get on with it and tell me what she is doing." (2/70).* Here, there is a clearer sense of a dyadic relationship with more reciprocity.

Similarly, she was able to observer her own responses more closely: "*... it has helped me chill out more around play time and just let her get on with things, cos I get stressed out with mess!" (4/126).* Helena is able to name something in herself and to differentiate between which elements of the dynamic between them are hers, and what comes from her child. She is able to own something of her own experience or reaction which is not to do with her child or their disability.

Noticing differences

Helena's observations here of the differences between herself and her child are more evident post-WMP. However, data both pre and post –WMP suggested that the opportunity to think and talk about your child furnished participants with the space to be able to notice things about them that had previously gone unnoticed. Joanne, when describing how her child responds to others, said

> *... for some reason she'll go to a man to be thrown around, but if she wants a drink or something to eat or help with the toilet, she'll come to me or my mum. Yeah, so I guess that's quite interesting actually how she's differentiated erm… who she can get what out if it. (6/212)*

Have been given an opportunity to take some time to describe her child's routines and relationships, Joanne was able to be more curious and to notice that her child differentiates between different kinds of people.

Similarly, the opportunity offered by the interview space to reflect on play also enabled participants to think about how their children challenge their preconceptions of what constitutes play. Joanne described feeling confused by her child's response to Peppa Pig:

> *…she's got Peppa books that she'll read but if I put Peppa Pig on the TV, then No Peppa Pig. Which I find quite interesting, and I don't know why, because she can't tell me why. (4/155)*

Joanne continued *"… I don't know what she does, it's like she potters around, faffing… I've never really gone into it this deep before". (6/212)*

I noted here a shift in tone from her feelings of exasperation to a sense that she was mulling it over. Her tone became one of bemusement and was not derogatory, as the word "faffing" might otherwise suggest. Whilst she recognises her child's activity as play, it is not the sort of play that she has encountered before, and she expresses an interest in thinking about it further.

It was interesting to note that across the data, play was rather concretely synonymous with toys. However, post WMP, Helena said

> *I was surprised how much she came out. I think because there wasn't the pressure of people. Even though we were watching, I think she could play automatically without hiding away... It shocked me a bit! (2/56)*

The word "automatic" demonstrates her recognition that her daughter has her own resources from which to draw for direction in her play without needing prompting. She is not shy, as might have been the expectation, and gravitated towards the attention of the adults rather than hiding from it. Helena's observation here indicates her greater confidence in her child's capacities as a result of her experience of WMP.

Helena also noted development in her child's play: "*...she's a bit more creative and so she can stay focussed on something for a little bit longer." (3/100).* I was interested to note that these comments are regulated (“a bit more”, “a little bit”). The differences that she notes are real, and not exaggerated in a manic way: there has been small but significant change. Interestingly, the emphasis is on the experience of play, rather than the toys or equipment used.

Feeling more connected

Pre-WMP, Joanne and Alice suggested that in some instances, the ways in which their children joined with others was predicated on needs they wanted to be met, rather than curiosity about others. Alice said, *“He’s a lovely boy when he wants to be” (1/15)* conveying a perhaps unconscious view that times when he is not “lovely” are within his control. This also suggests that she, equally unconsciously perhaps, imbues him with a sense of agency which at times can feel persecuting.

Joanne described how her child “*kind of calls upon people, she knows exactly what she wants from them” (3/122),* implying a similar experience of being on the receiving end of demands. These examples suggest a particular type of linking, one that implies possible manipulation on the part of the child and subservience on that of the adult. Whilst this was true for Helena pre-WMP too, as evidenced in phrases such as “*She likes doing things her own way, she doesn’t like doing it anyone else’s way!”*, (1/5), post-WMP, I felt that her experience of this had changed. She said of the experience of doing WMP at home:

> *…it was a little bit awkward at first because… she would be like what are you doing and tell me to shut up! ... it throws her off.* (1/23)

The emphasis here is on the child's experience of her mother; she is more able to take an observational stance and to be empathic, rather than feeling that controlling behaviour is combative or belligerent.

Post WMP, there was a slight shift towards recognising clinicians as people rather than depersonalised services which also contributed to the sub theme of feeling more connected. Jay said of their WMP clinician "*She was trying to help him, with his speech and his eye contact," (1/12),* indicating that he understood that the purpose was to support communication. He also commented that *"our sessions were on Thursdays",* (2/71), indicating that the WMP had a location in the week and, perhaps, also in his mind. Whilst it is unclear whether this is a change in his position from pre-WMP, his wife did express confusion in the pre-WMP data about where and from whom their child may receive support, and for what purpose.

Helena was more forthcoming about what she felt the benefits were of taking part in the intervention. She said:

> *I think it's quite good because you can see the kids playing. Like when we did our assessment, we literally only met one person at each time and even though she did get a diagnosis I can see how other people might not because it's such a short space of time. But if you had that time, like six weeks to actually watch the kid, I think that's helpful because everyone is different. (4/142)*

She suggests here that greater time observing and getting to know the child leads to greater confidence in the diagnostic result. She implies that others might not get a diagnosis because there was insufficient time for the team to really see the child, rather than that because they didn't meet diagnostic criteria.

Helena described feeling more confident when speaking about her child to professionals: “*I think it helped me seeing her play because then I could say to them as well.” (5/155).* This also suggests a change in perception about the diagnostic process: it is no longer an experience in which parents are expected to feel passive, but one in which she could take an active part.

Helena continued

> *Where I think this goes well alongside the assessment is that then they would have someone else to speak to about the kid, not just the parent because they can say, she does this, or she does that. I didn’t notice her hand flicking until we went into the play assessment thing, and so if she had had like 5 or 6 sessions with someone watching her play then I think that’s really helpful. (5/155).*

Here, she is advocating for the offer of WMP alongside the assessment process: the merits of this I will consider in the discussion section below.

4.1.4 Additional Finding: considering drop- out rate

The high level of dropout rate from the intervention can also be considered under the theme “seeing things in a new way”. Whilst I had imagined that the opportunity for support in the hiatus between assessment meetings may be welcomed by families, the fact that of 13 possible participants, one only completed all elements of the study suggests otherwise. I consider this further in the discussion session below.

5 Discussion

The study aimed to explore parents' experiences of WMP alongside the diagnostic assessment of their under-5-year-old's social communication difficulties and to address the two key research questions- firstly, the experiences of parents of under-5s going through the assessment process, and secondly, their experience of WMP at this time.

The three themes that emerged from the data analysis captured the ways in which the participants described their experiences of parenting a child with additional needs; their encounters with services and feelings about whether help has been accessible and possible. The findings indicate that for the participant who completed all parts of the study, small but arguably significant changes occurred in their experience of playing with their child and reflecting on the play alongside their WMP clinician. This participant advocated for the inclusion of WMP in the assessment process in the post-intervention feedback. The process of conducting the study raised interesting questions regarding the timing and purpose of offering WMP in relation to diagnostic assessment and whether the offer in conjunction with assessment is felt to be helpful or overwhelming.

I discuss the findings pertaining to each research question below:

1) What are the experiences of parents with an under-5s child who is presenting with possible communication difficulties who is undergoing an assessment process?

i) *Things don't join up:* parental experiences of clinicians and services before, during and after assessment

Pre-WMP interview data corresponded with Klauber's view (1998) that for some parents, the prospect of the formal diagnosis of your child's difficulties can be experienced as both persecuting and protracted, although contrary to Jacobs and colleagues study, (2019), there was no explicit mention of parental feelings of guilt or of feeling blamed by professionals. The data did suggest, as in Jacobs and colleagues' study, that parents sought certainty from the process, and in some cases felt that this would also offer validation of their own concerns and observations of their child's development which they felt had been overlooked or dismissed by some professionals during the process of securing a referral for diagnosis.

Reed and colleagues (2019), found that lengthier diagnostic processes and more developed clinician interpersonal relationships with parents resulted in greater parental resolve in response to diagnostic outcome. The findings support the idea that a stronger relationship with clinicians enables greater parental confidence in the process and participants' responses suggested that there were small changes in their thinking about the diagnostic process and in relating to their children. However, this was most evident in the feedback from the participant who had had most experience of the service historically and whom also had other family members with autism. This could imply that greater familiarity, and perhaps subsequent lesser anxiety, contributed to an overall more positive experience, as suggested by Voliovitch and colleagues (2021).

Of the four participants, one (who was familiar with the service and diagnostic assessment as had had experience with other family members) said that they understood that the assessment was to ascertain whether their child has autism specifically, three did not mention diagnosis but spoke about their worries about their child's presenting symptoms, particularly delayed language. Three of the four participants had had prior support from the wider children's services within which my team sits, such as speech and language or occupational therapies, or had met with paediatricians working in the team. The findings indicated participants' disjointed experiences with clinicians and services, and of the assessment process as a whole.

All participants referred to waiting times as a prominent feature, although for some this was frustrating and suggestive of incompetence or poor organisation on behalf of services. At times, it was experienced as abandoning and anxiety-provoking. For some participants who had had prior experience of the service, there was a stronger sense of resignation about long wait times rather than indignation. There was some differentiation between participants' feeling that individual clinicians were responsible for the wait as opposed to systemic constraints, although before WMP, clinicians tended to be synonymous with their profession or discipline rather than referred to as named individuals with whom families had working relationships.

Some participants explained that they felt that, at times, their expertise and knowledge of their children was discounted or ignored by professionals across a range of settings. They described their children's developmental histories, often noting turning points or specific milestones that were not yet met as specific areas of concern or preoccupation.

As the interviews took place before three of the four participants had had their assessment feedback meeting, it was not possible to ascertain from the data how the waiting within the assessment process was experienced by them and whether their feelings about it were informed by the result of the assessment. For the one participant whose child had been diagnosed with autism in between interviews, taking place in WMP alongside the assessment was reassuring as it meant that there was continual observation and thinking about her child, and an opportunity for her to contribute to the process, rather than just waiting for results. Interestingly, the participant felt that doing WMP alongside the assessment also offered opportunities for the WMP clinician to contribute to the diagnostic discussion, which would alleviate pressure on parents to be the sole contributor of information about what it was like to spend extended time with the child. In this study, the WMP clinicians did not contribute at all to the diagnostic discussion for ethical reasons. Equally, I had thought that were the clinicians to contribute, this might make taking part in the sessions feel more pressured for parents, as though it was a sort of examination. From this feedback, conversely, the possibility for greater collaboration was welcomed. Whether WMP clinicians should feed into the assessment process in this way needs further consideration, but this feedback supports Reed and colleagues' (2009) conclusion that longer, more involved diagnostic periods and better relationships with clinicians supports parental confidence in assessment results and recommendations.

Similarly, for other participants, the feeling that clinicians were secure in their prior knowledge of their child's developmental history rather than their having to begin again with each new referral was prized and added to feelings of greater confidence in services. Where this was not the case, participants were frustrated or confused about how and with whom they were speaking, which added further to feelings of disconnection with professionals.

I noted in my reflective journal how I felt differently positioned at various points throughout the interview process, varying from feeling that I was perceived as a part of services who had been experienced as unhelpful and dismissive and that taking part in the study would not offer anything of value; it was not enough and ultimately families would be left. This is interesting in relation to Delion's concept of the "black hole of despair" (2000); the gap between support and assessment experienced by some parents of children with autism in which they feel dropped. I felt a tension between my belief in the value of the intervention and an anxiety that it might not, used in this way, meet participant needs, and that participation in the study was not a guarantee of particular outcomes from WMP or from the diagnostic assessment itself.

The findings suggested that the prospect of their child being viewed by others outside of the family, including professionals was one that parents both wanted but also found difficult. For example, it is interesting to note that although I had not planned to use the prompt for question one routinely, it was needed at the beginning of all the interviews. Perhaps this indicated the level of anxiety that parents may have experienced about the interview setting and a concern about offering the "right" answer meant that further scaffolding was gratefully received by them. I noted too that on some occasions, I felt an incongruity between the broader descriptions given by some participants of the child's behaviour and demeanour and then the "three words" selected by the parent in response to this prompt. I wondered if this indicated a tension between describing their everyday lived experience authentically, and feelings of anxiety about ensuring that the researcher (i.e., me) would understand that they love and are proud of their child.

Clinician experience and input

This study did not include data gathered from clinician’s experience, or research into the levels of confidence in fostering appropriate interpersonal relationships felt either by those conducting the assessment or those offering WMP. All WMP clinicians in this study were qualified child psychotherapists and were therefore comfortable with working within the parameters of the psychoanalytic, observational approach of WMP. Houzel (1999) highlights the centrality of the supervision that practitioners in his team received as they delivered therapeutic observation in helping them to develop receptivity; it would be useful to ascertain whether the clinicians involved in the study felt that their routine supervision was sufficient, or whether opportunities to discuss their work within the scope of the study would have been beneficial; what they felt about the changes they observed in the families and indeed their own countertransference responses at different points of the intervention. This would have added a further dimension to the co-construction of the data.

ii) *It's a battle*: Experiences of parenting and relationships with my child

Analysis of the data suggested that participants strongly felt the need to advocate for their children and that they could experience situations in which they felt that their child’s needs were, or might be, misunderstood or not recognised appropriately. Participants spoke also about navigating differences in parenting approaches within the parental couple, which could cause tensions and frustrations. In these contrasting situations, participants described times of close proximity with their child, sharing almost identical feelings of discomfort or pain, and at other times, feeling huge distance between them, as though their child was entirely self-sufficient or far away.

This resonated with the psychoanalytic literature regarding children with autism's experience of premature separation, and Houzel's view that children in autistic states can deny otherness (2008). Here, in the parents' experience, otherness is avoided unconsciously either via the sense of being as one with their child, or by feeling that they are ignored or not needed.

The findings evidenced parents' experience of being at times rejected and also controlled by their children and supports Aquarone's view that it is necessary to consider impact of a child's disturbance on those who live with them. (Acquarone, 2018). However, the findings also demonstrated that these experiences were also accompanied by parents' delight in their children, although incidences of this were described less frequently. I wondered if in part, this is due to a deficit model that parents may experience in their dealings with professionals, in which difficulties must be emphasised if one is to receive appropriate support or be heard; or there is an unconscious assumption that clinicians are only concerned with what is wrong, rather than gaining an understanding of all aspects of a child's functioning and experience of their world, more akin with Alvarez's view about the need to support parents with understanding both autistic symptomatology and also the "intact" parts of the child's functioning. (Alvarez, 2005, p. 3). There is scope for more research to be done here.

The findings demonstrated that for some participants, moments in their child's developmental trajectory were experienced as turning points; not just the point of diagnosis as noted by Anderberg and South (2021) but also times when their child was felt to have regressed or not met an expected milestone. The intervention did not, as I had hoped, encourage a greater sense of diagnosis as a dynamic process rather than solely predicated on a fixed outcome. Conducting the interviews enabled me to greater understand the enormity of parents' experiences of managing the everyday alongside a diagnostic label which can feel abstract, regardless of whether it is welcome or expected. Acclimatising to both is a slow process and is highly personal. The data suggested that certainty in outcome was reassuring for some parents: something more fluid or dynamic may have been experienced as uncontaining at this time.

2) What are parents' experiences of undertaking WMP alongside the assessment process?

i) Seeing things in a new way: the value of play

Some participants' descriptions of their children's play illustrated that the opportunity to think about this enabled them to consider it in new ways and how playthings mean different things to their children in different contexts: such as one child who enjoyed Peppa Pig figurines but did not want to watch the cartoon on the television. Similarly, several participants spoke of their children's possessiveness over toys: disliking turn-taking or sharing with others (whether peers or parents themselves). Play was felt to be alien or incomprehensible, or excluding and relentless.

The findings suggested that taking part in WMP enabled the participant who completed the intervention to observe her child in new ways. The findings show that Helena and Jay were able to think about their child's play and therefore to notice more the ways that they relate to one another. Helena's responses showed how the facilitated space offered by the WMP sessions had enabled her to notice more, and therefore to engage more with their child, in something akin to Bion's "reverie" or alpha function (Bion, 1962). Helena's comments about the experience of watching their child play were more discursive post-intervention than the more concrete descriptions of toys in the pre-intervention data. Although Helena commented on the repetitiveness of their children's play before and after WMP, after the intervention she expressed less frustration and anxiety about this repetitiveness and perhaps more curiosity about her child's experience . Similarly, pre-WMP, Sabrina expressed frustration about their child's repetitive play. It is unclear whether Jay shared this view pre-WMP, but post WMP, he acknowledged that their child was interested in a greater range of playthings.

Alvarez's concept of reclamation (1992) is relevant here, as the more active role taken up by each participant perhaps enabled them to see their child's play as more varied and alive. Rather than holding more rigid expectations of what play should be like, there was more of an idea that play could be diverse.

ii) ***Seeing things in a new way*: taking a dual observational role**

When further considering the possible reasons why prospective participants may have changed their minds about taking part in the study, Maiello's observation of Tustin's concept of "adhesive at one-ness" in her patient was relevant (Maiello, 2001). As I have outlined above, WMP is grounded in a therapeutic observational approach, which requires separation in order to step into a third position from which to observe. This may have been unconsciously anxiety provoking for some, as an unconscious perceived threat to their psychic functioning rather than an offer of help to make contact with their child, as Maiello suggests.

One participant said that they were surprised both in their child's confident playing, but also in their own decreased stress levels. This correlates with Voliovitch and colleagues' study (2021) which similarly demonstrated that parental stress lessened when feelings of capability increased – here, the increased capability of both parent and child was perhaps felt to be mutually encouraging, in contrast to Rhode's "vicious cycle" (2018). This finding also suggests some movement in participant reflective functioning, as Kelly and colleagues state:

> A core element of maternal reflective functioning involves the mother's capacity to step back from her own affective experience in order to reflect upon her child's uniquely subjective intentions during moments of stress of conflict. (Kelly et al 2005, p. 301)

This is not to suggest that the difficulties of developing unconscious receptivity which Houzel referenced have been entirely overcome. There was evidence that one parent could better tolerate the irritation and frustration of their child's play in order to think about it with the support of their clinician. Although there were moments increased positive interaction as above, the data did not suggest that the intervention facilitated greater togetherness more consistently or allowed for the thought that play could be a shared rather than a solo activity. Feeling play perhaps to be only within the child's domain may have been influenced by parents' own individual childhood experiences of play with adults within their respective cultural backgrounds. In hindsight, I was curious about why I did not include interview questions that explored this further in either pre-or post-intervention data collection. Perhaps that fact that it had not occurred to me before reflects my own prior unconscious prejudice about where play belongs in a parent-child relationship, or that play is separate phenomena, rather than an integral part of parent-child communication.

Equally, both participants interviewed post-WMP found it harder to reflect on their child’s experience of WMP alongside their own. When asked, both said either that they did not think that their child would remember the experience, or that they did not feel that taking part in WMP had facilitated a change in their child’s thinking or presentation. They located the changes in themselves rather than in their children. This perhaps also implies that there is still further scope to explore parents’ perceptions about the impact of their undivided attention on their children, and the capacity that their children have to introject and to value experiences, as well as or instead of recalling them, even though they are not yet five years old.

Iii: Seeing things in a new way: thinking about the timing of the intervention

The number of families who dropped out of the study after they had expressed initial interest in taking part was striking and led to further thought about the experience of the offer of WMP at this particular time.

I hypothesised the following possible reasons for opt-in:

- keenness to take any support offered if beneficial: I wondered if families may feel a desire to receive as much support as possible, particularly perhaps after a long period of waiting

- previous participation in other studies: one participant talked about having been involved in a study before. Perhaps there was felt to be added value, or this had been a positive experience

- Feelings of isolation, keen to feedback into “system”: similarly, I wondered about the desire for ongoing contact with clinicians, or perhaps re-connecting if they have prior experience of the service and so it feels familiar

- Following instructions: I wondered about whether the invitation may have felt compulsory, or that there may have been fantasises about its impact on the diagnostic process, despite clear information to the contrary

The initial telephone calls resulted in a surprisingly high number of families withdrawing interest, having initially been keen to take part.

I wondered about the following possible reasons for drop out:

- Timing issues: does a diagnostic answer dominate at this point to the extent that there is not space for thinking about any other part of your child’s development?
- Childcare of siblings: some families felt that they were unable to commit to regular sessions and had childcare responsibilities for their other children
- Feeling overwhelmed: was the offer experienced as too much at this time?
- Confusion over what is mandatory and what is optional

- Increased anxiety as difficulties become more “real”: perhaps, having waited for some time for an assessment there was some emerging ambivalence about acknowledging their child’s difficulties. I wondered also about the use of the word “watch” in this context: whether this may feel persecuting or intrusive.

The reluctance to take part in the session evidenced by the drop out before the intervention, and then after the pre-WMP interview can perhaps be understood as a communication that the offer was experienced as overwhelming, or not desirable at this time. The two participants who completed the pre-WMP interviews but did not take part in WMP cited time restraints and wider family and childcare commitments as reasons why they felt unable to proceed. Whilst externally this may be the case, it is interesting to think about possible unconscious ambivalence about what, in phantasy, maybe seen or exposed. Further research into the offer of WMP at other time points may offer helpful contrast to illuminate some of these possible experiences and barriers to engagement at this time.

6 Conclusion

The study aimed to learn about parent’ experiences of WMP alongside the process of diagnostic assessment of their child’s social communication difficulties including possible autism. WMP is informed by key principles of child and adolescent psychoanalytic psychotherapy including the value of close observation in strengthening containment. My experience of WMP within my own clinical practice had informed my belief in the value of the approach and I hoped that this study would support the NICE guidelines recommendation of play-based interventions for under-5s newly diagnosed with social communication disorders. Although the findings were slight, the study did, in my view, begin to support these. Whilst the findings did not demonstrate improved functioning in terms of the children's social communication, they did demonstrate small but arguably significant changes in parental capacity for noticing and attending to their child's play and communication. Likewise, the study demonstrated that WMP could help some parents to feel more secure in the assessment process.

6.1 Brief summary of findings

The findings, perhaps unsurprisingly, reiterated the significance and benefit of personalised, sensitive relationships with clinicians that are developed over a period of time in fostering greater confidence in the diagnostic process and in the service, but also in enabling parents to experience shared curiosity in their child and the way that he or she relates to them. There was also evidence that parents valued the opportunity to talk in a more open-ended way about their experiences of parenting and that the opportunity to do so allowed for greater reflection and curiosity than perhaps they felt there was space for within their everyday lives or within appointments with clinicians that are more task orientated. The study indicated the importance of the involvement of parents as active parts in the assessment process. It also demonstrated the significance of having a participating third in their experience of being with their child and observing them. This "third" also crucially provided the space for reflections where both the parent and the child are taken into account.

6.2 Limitations of the study

An obvious limitation of this study is its size. The sample group comprised only four participants, of which only one completed all stages of the project and so findings cannot be presented as conclusive. However, analysis of the data suggested that WMP can have positive effect on parents' confidence and curiosity in their child alongside strengthening relationships with professionals and services. Similarly, it can help to make assessment feel more personalised.

During the recruitment phase I noted my surprise at the number of potential participants who initially expressed an interest in the study and then subsequently changed their minds. This mismatch was further borne out during the data collection period when two participants no longer wished to continue, citing their concerns about the time commitment alongside their other family responsibilities as the reason that further participation was not possible for them. For some possible participants, withdrawal may have been an unconscious retaliation in response to the frustration of having to wait extended periods of time before being offered an appointment. For others, it may imply ambivalence about the prospect of diagnosis: the desire not to know and possible anticipated anxiety about the turning point of assessment, as Anderberg and South (2021) explored. There may also have been concerns about being perceived as to blame for their child's difficulties, as Anne Spoladore (2013) advised.

Similarly, although one participant felt WMP was a helpful addition alongside diagnostic assessment, the high drop-out levels suggest that for others, the timing is not conducive as the assessment process can feel overwhelming in and of itself. For one participant, there was confusion regarding the purpose of WMP at this time (it did not inform the overall decisions made by clinicians about whether diagnostic criteria had been met). As an intervention that aims to foster greater attunement between parent and child it may have been misunderstood as an implied comment about or criticism of current lack of attuned care, rather than being seen as an opportunity to engage more actively with the assessment process.

6.3 Strengths of the study

The study was an opportunity to hear directly from parents about their personal experiences of assessment. Although a small group, they are reflective of the population who access the clinic and the wider service. The comprehensive literature review is also a strength as it begins to join up psychoanalytic thinking about diagnosis with the practical routine processes offered by services.

6.4 Experience of carrying out the study

Overall, I found the process of conducting this study illuminating both in terms of this research question, but also in considering the role of the feedback interview in ascertaining patient experience and its possibility for informing subsequent service evaluation more widely. I had expected that support in conjunction with diagnostic assessment offered sooner rather than later would be well received, although the findings did not suggest that this was necessarily the case.

This study enabled me to think more closely about my dual role as a child psychotherapist and an NHS clinician, and how this impacts the way I am perceived by patients and positioned in the transference as a result. Reflecting on the questions that I didn't ask participants, such as those that may have established more about their prior thought and their experiences of and feelings about diagnostic labels; where there may have been needs in the family already; attitudes towards play both in participants' wider cultural experience and more immediately within their own family histories, highlighted my own preoccupation with the immediate task in hand, an interesting parallel with my fantasy of parents' preoccupation with diagnostic result as opposed to wider dynamic thinking about their child, and the need to focus only on one thing at a time. My focus on the particularity of the experience of the intervention as a moment in time perhaps meant that I was blinkered in considering participants' more epistemological positions. Further exploration into these areas would have offered more complexity and richness to the study and may have offered more food for thought about the parental experience of receiving no unifying diagnosis, and what support may help families to reflect on this and how best to understand their child's needs without the boundaries of a diagnostic term.

6.5 Recommendations for practice

The study poses a number of interesting points for consideration if WMP is to be included in the MDAT offer moving forwards.

The study supports the idea that diagnostic conversation must be approached sensitively and in the spirit of collaboration to mitigate against possible feelings of blame or criticism and to ensure that positive therapeutic relationships can be fostered and sustained. The role of the WMP clinician is pivotal if the offer of support is to be taken up, consciously and unconsciously, as it is intended. Both participants named their WMP clinician in the post-intervention data and linked them with a sense of clinical purpose which demonstrated greater confidence in what they were doing, and indicated a more personalised relationship that the homogenised services that were referenced in the pre-WMP data. The location of the WMP sessions was also important to both parents and children, as evidenced in post-intervention interviews by references to the times of the week and the name of the room in which sessions took place. This conjured a stronger sense of play being purposeful and located, facilitated by the support and encouragement of their practitioner.

I have discussed the timing of the intervention above and the conflicting views that participants had about whether taking part alongside assessment was felt to be helpful or overwhelming. It may be that this is something that could be offered at different time points, depending on family capacity and preference. Offering WMP as a post-diagnosis intervention may also help families with thinking more about their child’s play and communication within the context of the outcome of the assessment, and what the outcome may mean for both family and child.

This study serves as a starting point for further discussion about both the value of child led play with this population of patients, but also for the role that psychoanalytically informed discussion could play as a component of diagnostic assessment more generally. This could be used in a more formalised way as WMP clinician feedback to the MDAT assessing team or child psychotherapy facilitation of reflective discussion about clinicians’ observations of the child’s play in the assessment meetings.

6.6 Recommendations for further research

This study was conducted by child psychoanalytic psychotherapists. It would be interesting to explore whether offering WMP training to all assessing clinicians and encompassing some therapeutic observation within the assessment would inform the diagnostic discussion impacts on the conversations that are held with families about possible diagnosis, and the subsequent experiences of families and clinicians.

The study has highlighted the call for needs-led assessment and feedback and support for families whose children’s needs are not easily recognised using specific diagnostic criteria. Further research into whether WMP can support families whose children are not given a unifying diagnosis would be beneficial, particularly in exploring how parents experience this outcome and how best they can feel that their child’s needs are still recognised and can be supported.

Further consideration of the reluctance to take up the offer of WMP should be explored in conjunction with the experience of professionals training in the model who, having expressed interest and enthusiasm, do not go on to implement it routinely in their services. It is important to consider whether there are parallels in the reticence of both possible practitioners and the possible participants of this study and whether this is due to anxieties about the observational component, familiar to professionals who work psychoanalytically, but perhaps not to others from disciplines which do not routinely engage in observation of this kind. Additionally, further research into attitudes towards play would be beneficial. In particular, parents' and practitioners' own childhood experiences of play and the ways in which play is viewed across a wider range of cultural contexts would further support thinking about the ways in which WMP can be used to support this client group.

Conducting the interviews demonstrated to me the important feedback that can be gained from greater consultation with families about their experiences of services that perhaps cannot be gleaned from routine questionnaire or monitoring tools frequently used in CAMHS services. These tools ascertain some information about whether families feel supported and are happy with the service that they received, but they do not allow for clinicians to understand the patient experience in greater depth: what has been taken in from the experience and how patients' descriptions of their experience demonstrate how their internal positioning may have changed as a result of treatment. More research into the use of open-ended, discursive service user feedback would allow for this.

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Appendices

Participant information sheet

NHS
The Tavistock and Portman
NHS Foundation Trust

Participant Information Sheet

Project Title

How do parents experience “Watch Me Play!” alongside the multi-disciplinary assessment of their under-five year old’s developmental disability?

Who is conducting this research?

My name is Cath Hunter and I am a Child and Adolescent Psychotherapist in Doctoral Training studying at the Tavistock and Portman NHS Foundation Trust. I also work for MOSAIC CAMHS and South Camden Open Minded. This project is being sponsored and supported by The Tavistock and Portman Centre and has been through all relevant ethics approval. This course is overseen and certified by The University of Essex. I have designed the study and will conduct the interviews and data analysis.

What is the purpose of this study?

In this study I hope to explore parents’ experience of taking part in “Watch Me Play!” alongside the assessment of their child in the Child Development Team at MOSAIC. I am keen to find out whether families think that we should include “Watch Me Play!” alongside the assessment process in the future.

What is “Watch Me Play!”?

“Watch Me Play!” is designed to promote child-led play and to support relationships between parents and carers and their children. A special time is set aside for play in which the child receives the adult’s undivided attention, which helps the child to focus on their play and communication. Alongside the time at home to play, parents meet with a clinician to talk about what they have noticed in their child’s play, and how it made them feel.

For more information about this approach, visit

www.tavistockandportman.nhs.uk/care-and-treatment/our-clinical-services/watch-me-play/

What will taking part in the study involve?

You will be invited to take part in Watch Me Play!, which is made up of up to six 50-minute sessions with one of my colleagues from the Child Development team at MOSAIC. I will meet with you for approximately an hour before these sessions commence, and again after you have completed them. In these sessions I will interview you about your initial thoughts before and then reflections about how you found this experience. All interviews will be audio recorded. During the interview I will ask some questions as prompts, but it will largely be a chance for you to talk freely about the experience of Watch Me Play!

Taking part in both the study and in Watch Me Play! will have no bearing on the outcome of your child’s CDT assessment and will not impact any other assessment or treatment that you receive from MOSAIC services. My colleague and I will meet with you before the sessions and interviews so we can talk about how to arrange them and answer any questions you might have before we begin.

Who can take part in the study?

All participants will be parents/carers of children who are on the waiting list for assessment by the Child Development Team.

Do I have to take part?

There is no obligation to take part in this study and it is your choice whether or not you decide to be involved. If you do agree to take part then you can then withdraw your data without giving a reason up to three weeks after our first interview. If you do decide to withdraw from the research all data collected from you will be permanently destroyed and not used in the data analysis. There is a three-week limit as after this point I will have begun to analyse and process the data collected.

How will the recorded data be used?

The recorded interviews will be transcribed and analysed by me and will form the data for my doctoral thesis that I am completing as part of my studies. It may also be used in future academic presentations and publications. All audio recordings from the interviews will be destroyed by the time the projected is completed. During the transcription process I will anonymise any identifying details to maintain the confidentiality of those involved or being talked about in the study. As such any identifying details will have been anonymised in the final doctoral thesis or any future publication of the work. Confidentiality may be limited in the event where a participant discloses imminent harm to themselves or others.

What will happen to the recorded data?

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 up to 10 years after the study has finished. The interview will be audio recorded and transcribed by myself.

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. I am the only person 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.

All electronic data will be stored on a password protected computer. Any paper copies will be kept in a locked filing cabinet. All audio recordings will be destroyed after completion of the project. Data from the study will be retained, in a secure location, for 10 years. Electronic data will be password protected and any physical copies will be stored in a lockable filing cabinet.

If you would like more information on the Tavistock and Portman and GHC privacy policies please follow these links:

https://tavistockandportman.nhs.uk/about-us/contact-us/about-this-website/your-privacy/

You can find out more about the legal framework within which your information will be processed by contacting the sponsoring Trust's Interim Clinical Governance and Quality Manager, Beverley Roberts.

Are there any benefits to taking part?

It is hope that you will find the experience an enjoyable and helpful one, and that it will support you and your child throughout your experiences of their assessment with CDT.

Are there any risks to taking part?

There are no direct risks to taking part in this study. However, there is a time commitment and you may find that thinking in greater depth about how your child experiences their world can be difficult as well as rewarding. Throughout the process, you will be supported by your Watch Me Play! clinician and have access to consultation with other MOSAIC clinicians should you feel that this would be helpful.

Contact Details

Please do not hesitate to contact me if you have questions about the project or would like to discuss anything further.

Cath Hunter

Email: chunter2@tavi-port.nhs.uk

Address: MOSAIC CAMHS

Alternatively, any concerns or further questions can be directed to my supervisor:

Dr Jenifer Wakelyn

Email: jwakelyn@tavi-port.nhs.uk

If you have any concerns about the conduct of this research, the researcher or any other aspect of this research project please contact:

Beverley Roberts, Interim Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk).

Thank you for considering taking part in this study and taking the time to read this information. If you are willing to take part in the research please complete the consent form provided

Participant Consent Form

NHS
The Tavistock and Portman
NHS Foundation Trust

Participant Consent Form

Project Title: How do parents experience “Watch Me Play!” alongside the multi-disciplinary assessment of their under-five year old’s developmental disability?

Name of Researcher: Cath Hunter

1) I confirm that I have read and understood the Participant Information Sheet and have been given time to consider its contents. I confirm I have been given time to ask any questions I have about the study and these have been answered satisfactorily.	
2) I understand that participation in this study is voluntary and I am free to withdraw at any time without giving a reason, or withdraw any unprocessed data previously supplied. I understand that I can withdraw my data up to three weeks after the interview has taken place.	
3) I understand that the interviews will be audio recorded and transcribed by the researcher as described in the Participant Information Sheet.	
4) I understand that information I give in the interviews will be kept confidential by the researcher unless I or anyone else is determined to be at risk.	
5) I understand that whilst every effort will be made to ensure participant anonymity, the research participant group is small which may mean that it is easier to identify participants than if the group was bigger.	

6) I understand that participant confidentiality would need to be reconsidered in the occurrence of disclosure of harm to self or others.	
7) I understand that direct quotes from the interviews may be used in this research study but will be anonymised and held securely by the researcher.	
8) I understand that the results of this research will be published as part of a Doctoral Thesis and may form part of future publications or academic presentations.	
9) I understand that all data collected from the interview will be destroyed no longer than 5 years after the study has finished.	
10) I understand the interviews may involve the risk of emotional upset or discomfort, that I can stop the interview at any point and that I will be offered a chance to debrief after the interview has concluded.	

I confirm that I _______________(Participant Name) have understood all of the above and what is required of me and I consent to participate in this study.

Participant’s Name (Printed):___________________________________

Participant’s Signature:____________________________ Date:____________

Researcher: Cath Hunter

Signature: ______________________

Date: __________________________

Contact Details:

Researcher: Cath Hunter Email: chunter2@tavi-port.nhs.uk

Supervisor : Dr Jenifer Wakelyn Email: jwakelyn@tavi-port.nhs.uk

Thank you for agreeing to take part in this study.

Your contribution is very much appreciated.

Ethical approval (TREC)

The Tavistock and Portman NHS
NHS Foundation Trust

Tavistock and Portman Trust Research Ethics Committee (TREC)

APPLICATION FOR ETHICAL REVIEW OF STUDENT RESEARCH PROJECTS

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact Paru Jeram (academicquality@tavi-port.nhs.uk)

FOR ALL APPLICANTS

If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters. You need only complete sections of the TREC form which are NOT covered in your existing approval

Is your project considered as 'research' according to the HRA tool? (http://www.hra-decisiontools.org.uk/research/index.html)	Yes
Will your project involve participants who are under 18 or who are classed as vulnerable? (see section 7)	No
Will your project include data collection outside of the UK?	No

SECTION A: PROJECT DETAILS

Project title	How do parents experience “Watch Me Play!” alongside the multi-disciplinary assessment of their under-five year old’s developmental disability? An Interpretative Phenomenological Analysis		
Proposed project start date	October 2021	**Anticipated project end date**	**September 2023**
Principle Investigator (normally your Research Supervisor): Jenifer Wakelyn			
Please note: TREC approval will only be given for the length of the project as stated above up to a maximum of 6 years. Projects exceeding these timeframes will need additional ethical approval			
Has NHS or other approval been sought for this research including through submission via Research Application System (IRAS) or to the Health Research Authority (HRA)?	**YES (NRES approval)** ☐ ☐ **YES (HRA approval)** ☐ **Other** ☒ **NO**		
If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters.			

SECTION B: APPLICANT DETAILS

Name of Researcher	Cath Hunter
Programme of Study and Target Award	DProf Child Psychoanalytic Psychotherapy
Email address	Chunter2@tavi-port.nhs.uk
Contact telephone number	07967 234436

SECTION C: CONFLICTS OF INTEREST

Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research? **YES** ☐ **NO** ☒ If **YES**, please detail below:
Is there any further possibility for conflict of interest? YES ☐ **NO** ☒
Are you proposing to conduct this work in a location where you work or have a placement? **YES** ☒ **NO** ☐ If **YES**, please detail below outline how you will avoid issues arising around colleagues being involved in this project:
The intervention will be carried out by my colleagues and all subsequent research activity – interviews, analysis, writing – will be conducted solely by me and overseen by my supervisor. All material from clinicians and patients will be anonymised

Is your project being commissioned by and/or carried out on behalf of a body external to the Trust? (for example; commissioned by a local authority, school, care home, other NHS Trust or other organisation). *Please note that ‘external’ is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)	**YES** ☐ **NO** ☒
If **YES**, please add details here:	

Will you be required to get further ethical approval after receiving TREC approval? If **YES**, please supply details of the ethical approval bodies below AND include any letters of approval from the ethical approval bodies (letters received after receiving TREC approval should be submitted to complete your record):	**YES** ☒ **NO** ☐
If your project is being undertaken with one or more clinical services or organisations external to the Trust, please provide details of these:	
CNWL Trust	
If you still need to agree these arrangements or if you can only approach organisations after you have ethical approval, please identify the types of organisations (eg. schools or clinical services) you wish to approach:	
CNWL – MOSAIC Integrated services for Children with Disabilities have confirmed that the project can proceed	
Do you have approval from the organisations detailed above? (this includes R&D approval where relevant) Please attach approval letters to this application. Any approval letters received after TREC approval has been granted MUST be submitted to be appended to your record	**YES** ☒ **NO** ☐ **NA** ☐

SECTION D: SIGNATURES AND DECLARATIONS

APPLICANT DECLARATION

I confirm that:

- The information contained in this application is, to the best of my knowledge, correct and up to date.
- I have attempted to identify all risks related to the research.
- I acknowledge my obligations and commitment to upholding ethical principles and to keep my supervisor updated with the progress of my research
- I am aware that for cases of proven misconduct, it may result in formal disciplinary proceedings and/or the cancellation of the proposed research.
- I understand that if my project design, methodology or method of data collection changes I must seek an amendment to my ethical approvals as failure to do so, may result in a report of academic and/or research misconduct.

Applicant (print name)	C F Hunter
Signed	Catherine Hunter
Date	27/1/22

FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY

Name of Supervisor/Principal Investigator	Jenifer Wakelyn Jwakelyn@tavi-port.nhs.uk

Supervisor –

- Does the student have the necessary skills to carry out the research?
  YES v☐ NO ☐
- Is the participant information sheet, consent form and any other documentation appropriate?
  YES v☐ NO ☐
- Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient?
  YES v☐ NO ☐

▪ Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance? **YES v☐ NO ☐**	
Signed	Jenifer Wakelyn
Date	27/1/22

COURSE LEAD/RESEARCH LEAD Does the proposed research as detailed herein have your support to proceed? YES ☒ NO ☐	
Signed	Brinley G. Yare DIGITAL SIGNATURE
Date	27/1/22

SECTION E: DETAILS OF THE PROPOSED RESEARCH

1. **Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)**
This study aims to explore how parents experience the offer of “Watch Me Play!” (WMP) alongside the process of diagnostic assessment for their under 5-year-old. The study will consider whether parents/carers of under-5s who are presenting with possible developmental disability find the experience of WMP contributes towards building confidence in understanding and supporting their child; if the experience of having a professional to talk to about their child’s play is helpful alongside other types of conversations within the assessment process, and in what ways, if at all, the intervention impacts on the family’s thoughts about how their child experiences their disability. 4-8 participants will be recruited to take part in the project from the top of the waiting list for developmental assessment with the Child Development Team in Mosaic integrated services for children with disabilities. They will be invited to take part by being offered a participant information sheet and follow up conversation during which my service supervisor will talk through the project with anyone who may be interested in taking part. This initial approach will be carried out by my service supervisor or colleagues in the team who are neither me nor the clinicians delivering the WMP intervention. I will not be involved in the delivery of the intervention and will conduct the pre/post intervention interviews only.

Once they have completed the consent form, participants will be required to take part in the following:

i) Introductory meeting (up to 1 hour)

Each participant will meet with the clinician with whom they will undertake Watch Me Play! And the researcher. In this meeting we will:

- explain the outline of the project and its aims, reiterate confidentiality and expectations/consent
- explain that this project aims to offer sessions which may support the assessment process, but forms no part of the child's assessment and will have no baring on the outcome of the assessment or future involvement with any part of Mosaic Integrated services
- Talk through the Watch Me Play! leaflet and offer participants the Manual for Parents if they would like to read further as well as the diary sheet
- Agree dates for sessions and pre/post interviews

ii) Pre-introduction semi- structured interview (1 hour) to commence week beginning 25 April 2022

Each participant will meet individually with the researcher to discuss their child, their expectations and thoughts about the project and the assessment process. I will audio record and transcribe these for analysis.

iii) Watch Me Play! Sessions (up to 6 weekly 1 hour sessions) to commence week beginning 3 May 2022

Participants will take part in once weekly Watch Me Play! sessions with the same clinician from the Child Development Team each week. They will be offered the Watch Me Play! Diary sheet to accompany these. This is optional and will form part of the data for analysis within the project if they choose to do this.

iv) Post- intervention semi- structured interview (1 hour) to commence week beginning 4 July 2022

Each participant will meet individually for a second time with the researcher to discuss their experience of taking partin Watch Me Play! Alongside other support and assessment that they are taking part in within the service.

After the project, participants will be thanked by letter and offered a short summary of the project and its findings if they would like it.

2. Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed

research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)

I have discussed this proposal with colleagues and managers in both services who deem it feasible and helpful in terms of their wider remits of building family engagement and parental confidence in supporting their children. It is hoped that this project will establish whether offering Watch Me Play alongside the battery of assessment used to diagnose developmental disabilities in under 5s is experienced as a helpful support, and that it will give families a greater sense of agency within their experience of the assessment process. I aim to explore the following:

- Do parents/carers of under-5s who are presenting with possible developmental disability find the experience of WMP contributes towards building confidence in understanding and supporting their child?
- Is the experience of having a professional to talk to about their child's play helpful alongside other types of conversations within the assessment process?
- In what ways, if at all, does taking part in a psychoanalytically informed intervention impact on the family's thoughts about how their child experiences their disability?
- Might this project support the establishment of WMP as an intervention within the routine practice of the Child Development Team?

This project sits within the wider community of ongoing research, training and innovation regarding Watch Me Play!

3. **Provide an outline of the methodology for the proposed research, including proposed method of data collection, *tasks* assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)**

Participants will be invited to take part in semi-structured, in-depth interviews, pre and post intervention. The data collected from these will be analysed using Iinterpretetive Phenomenological Analysis (IPA) to examine the ways in which parents make sense of the experience of the assessment of their child's presentation and what, if anything, their involvement in a psychoanalytically informed therapeutic component may add to their perceptions of this, and their aspirations moving forwards. I have chosen IPA as the methodology for this project due to its idiographic approach and its appropriateness for small sample groups.

Interviews pre and post intervention will be audio recorded and then I will transcribe and analyse these. Semi-structured interviews will make use of the pre-published Watch Me Play! guidance for clinicians and families will be offered the Watch Me Play! diary to complete during the intervention if they would like to do so – although this is optional.

SECTION F: PARTICIPANT DETAILS

4. Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why these criteria are in place. (Do not exceed 500 words)

This is a single cohort design. Eligibility is determined by the fact that families have been referred to the Child Development Team for assessment and are on the waiting list. I intend to recruit 4-8 participating families to ensure that sufficient rich material emerges from the interview stages.

Families who are at the top of the waiting list or at the beginning of the assessment process will be invited to take part via email and telephone/ in person conversation, depending on family's stage within the assessment process to ensure that their engagement with Watch Me Play! is concurrent with other assessment processes. They will be invited by my service supervisor or a colleague who is not involved in the intervention and not by me.

It will be explained to potential participants that following attendance at an introductory meeting this is a project in three parts: pre-interview, intervention, post interview. Participation in all three parts is required for inclusion in the study.

5. Please state the location(s) of the proposed research including the location of any interviews. Please provide a Risk Assessment if required. Consideration should be given to lone working, visiting private residences, conducting research outside working hours or any other non-standard arrangements.

If any data collection is to be done online, please identify the platforms to be used.

This project will be undertaken within the Child Development Team (CDT); a multi-disciplinary team within the wider integrated services for children with disabilities within the London Borough in which I work. CDT offer multi-disciplinary assessment and diagnostic work for under-5s presenting with complex needs and possible developmental difficulties. The team is in-part comprised of professionals within my CAMHS team who work across both services. Both the intervention and the interviews will take place in person in the clinic.

6. Will the participants be from any of the following groups?*(Tick as appropriate)*

☐ Students or Staff of the Trust or Partner delivering your programme.

☒ Adults (over the age of 18 years with mental capacity to give consent to participate in the research).

☐ Children or legal minors (anyone under the age of 16 years)[1]

☐ Adults who are unconscious, severely ill or have a terminal illness.

☐ Adults who may lose mental capacity to consent during the course of the research.

☐ Adults in emergency situations.

☐ Adults[2] with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).

☐ Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).

☐ Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).

☐ Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).

☐ Healthy volunteers (in high risk intervention studies).

☒ Participants who may be considered to have a pre-existing and potentially dependent[3] relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).

☐ Other vulnerable groups (see Question 6).

☐ Adults who are in custody, custodial care, or for whom a court has assumed responsibility.

☐ Participants who are members of the Armed Forces.

[1] *If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability[3], any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.*

[2] *'Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning*

difficulties or receiving care in their own home, or receiving hospital or social care services.' (Police Act, 1997)

[3] Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.

7. **Will the study involve participants who are vulnerable? YES ☐ NO ☒**

For the purposes of research, 'vulnerable' participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from:

- the participant's personal characteristics (e.g. mental or physical impairment)
- their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness).
- where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable
- children are automatically presumed to be vulnerable.

7.1. If YES, what special arrangements are in place to protect vulnerable participants' interests?

If YES, a Disclosure and Barring Service (DBS) check **within the last three years** is required.

Please provide details of the "clear disclosure":

Date of disclosure: 2/7/19

Type of disclosure:none

Organisation that requested disclosure:Tavistock and Portman NHS Foundation Trust (employer)

DBS certificate number:001663952085

*(NOTE: information concerning activities which require DBS checks can be found via https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance). Please **do not** include a copy of your DBS certificate with your application*

8. **Do you propose to make any form of payment or incentive available to participants of the research? YES ☐ NO ☒**

If **YES**, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

9. **What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)**

Materials in translation and interpreting services will be employed for participants who may find this of use. Participants may also wish to be accompanied by an advocate of their choice, if this is their preferred way of working with professionals.

SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT

10. Does the proposed research involve any of the following? *(Tick as appropriate)*

☐ use of a questionnaire, self-completion survey or data-collection instrument (attach copy)

☐ use of emails or the internet as a means of data collection

☐ use of written or computerised tests

☒ interviews (attach interview questions)

☒ diaries (attach diary record form)

☐ participant observation

☐ participant observation (in a non-public place) without their knowledge / covert research

☒ audio-recording interviewees or events

☐ video-recording interviewees or events

☐ access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes

☐ administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process

☐ performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction

☐ Themes around extremism or radicalisation

☐ investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)

☐ procedures that involve the deception of participants

☐ administration of any substance or agent

☐ use of non-treatment of placebo control conditions

☐ participation in a clinical trial

☐ research undertaken at an off-campus location (risk assessment attached)

☐ research overseas (please ensure Section G is complete)

11. **Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life?**

    YES ☐ **NO** ☒

    If **YES**, please describe below including details of precautionary measures.

12. **Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.**

N/A

13. **Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)**
    NOTE: Where the proposed research involves students , they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

I hope that parents/carers of under-5's who are presenting with possible developmental disability will find that the experience of WMP contributes towards building their confidence in understanding and supporting their child and that the experience of having a professional to talk to about their child's play will be helpful and illuminating when considered alongside other types of conversations within the assessment process. I hope that the inclusion of WMP may enable familes to feel a greater sense of agency during their child's assessment for developmental disability. Taking part in a psychoanalytically informed intervention may also support the family in thinking about how their child experiences their disability.

14. **Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)**

Participants are free to withdraw from the study at any point, and will be given the contact details of my service manager and research supervisor in case of emergency. Should adverse circumstances prevent me from continuing with the research, participants will be informed by my research supervisor and will be informed of this possible (unlikely) eventuality before beginning the intervention.

15. **Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants.**

Participants will be offered the contact details of the Tavistock and Portman Academic Governance and Quality Assurance team, my research supervisor and me should they wish to have further discussion after the research period has been completed. As this intervention sits alongside ongoing assessment, they will have continued support from clinicians assessing and supporting their child, as well as subsequent signposting once assessment has been completed.

16. **Please provide the names and nature of any external support or counselling organisations that will be suggested to participants if participation in the research has potential to raise specific issues for participants.**

MOSAIC CAMHS – MOSAIC integrated services for children with disabilities – CNWL

17. **Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)**

N/A

<u>FOR RESEARCH UNDERTAKEN OUTSIDE THE UK</u>

18. Does the proposed research involve travel outside of the UK?
☐ **YES** ☒ **NO**

If YES, please confirm:

☐ I have consulted the Foreign and Commonwealth Office website for guidance/travel advice? http://www.fco.gov.uk/en/travel-and-living-abroad/

☐ I have completed ta RISK Assessment covering all aspects of the project including consideration of the location of the data collection and risks to participants.

All overseas project data collection will need approval from the Deputy Director of Education and Training or their nominee. Normally this will be done based on the information provided in this form. All projects approved through the TREC process will be indemnified by the Trust against claims made by third parties.

If you have any queries regarding research outside the UK, please contact academicquality@tavi-port.nhs.uk:

Students are required to arrange their own travel and medical insurance to cover project work outside of the UK. Please indicate what insurance cover you have or will have in place.

19. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place. Please also clarify how the requirements will be met:

N/A

SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL

20. **Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

21. **Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

22. **The following is a <u>participant information sheet</u> checklist covering the various points that should be included in this document.**

☒ Clear identification of the Trust as the sponsor for the research, the project title, the Researcher and Principal Investigator (your Research Supervisor) and other researchers along with relevant contact details.

☒ Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.

☒ A statement confirming that the research has received formal approval from TREC or other ethics body.

☒ If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.

☒ A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.

☒ Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.

☒ Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.

☒ A statement that the data generated in the course of the research will be retained in accordance with the Trusts 's Data Protection and handling Policies.: https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/

☒ Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Beverley Roberts, Interim Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

23. The following is a consent form checklist covering the various points that should be included in this document.

☒ Trust letterhead or logo.

☒ Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.

☒ Confirmation that the research project is part of a degree

☒ Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.

☒ Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.

☒ If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.

☒ The proposed method of publication or dissemination of the research findings.

☒ Details of any external contractors or partner institutions involved in the research.

☒ Details of any funding bodies or research councils supporting the research.

☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

SECTION H: CONFIDENTIALITY AND ANONYMITY

24. Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.

☐ Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?

☐ The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).

☒ The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).

☐ Participants have the option of being identified in a publication that will arise from the research.

☒ Participants will be pseudo-anonymised in a publication that will arise from the research. (I.e. the researcher will endeavour to remove or alter details that would identify the participant.)

☒ The proposed research will make use of personal sensitive data.

☒ Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

25. Participants must be made aware that the confidentiality of the information they 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 only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations.

YES ☒ **NO** ☐

If **NO**, please indicate why this is the case below:

NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE

WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.

SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT

26. Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES ☒ NO ☐ If **NO**, please indicate what alternative arrangements are in place below:
27. In line with the 5th principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for. ☐ 1-2 years ☐ 3-5 years ☒ 6-10 years ☐ 10> years **NOTE: In line with** Research Councils UK (RCUK) guidance, doctoral project data should normally be stored for 10 years and Masters level data for up to 2 years

28. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.

☒ Research data, codes and all identifying information to be kept in separate locked filing cabinets.

☐ Research data will only be stored in the University of Essex OneDrive system and no other cloud storage location.

☒ Access to computer files to be available to research team by password only.

☐ Access to computer files to be available to individuals outside the research team by password only (See **23.1**).

☒ Research data will be encrypted and transferred electronically within the UK.

☐ Research data will be encrypted and transferred electronically outside of the UK.

NOTE: Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

Essex students also have access the ‘Box’ service for file transfer: https://www.essex.ac.uk/student/it-services/box

☐ Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.

☒ Collection and storage of personal sensitive data (e.g. racial or ethnic origin, political or religious beliefs or physical or mental health or condition).

☒ Use of personal data in the form of audio or video recordings.

☐ Primary data gathered on encrypted mobile devices (i.e. laptops).

NOTE: This should be transferred to secure University of Essex OneDrive at the first opportunity.

☒ All electronic data will undergo secure disposal.

NOTE: For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard ‘secure empty trash’ option; an alternative is Permanent eraser software.

☒ All hardcopy data will undergo secure disposal.

NOTE: For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

29. Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.

N/A

30. Please provide details on the regions and territories where research data will be electronically transferred that are external to the UK:

N/A

SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS

30. How will the results of the research be reported and disseminated? *(Select all that apply)*

☒ Peer reviewed journal

☐ Non-peer reviewed journal

☒ Peer reviewed books

☐ Publication in media, social media or website (including Podcasts and online videos)

☒ Conference presentation

☒ Internal report

☐ Promotional report and materials

☐ Reports compiled for or on behalf of external organisations

☒ Dissertation/Thesis

☐ Other publication

☒ Written feedback to research participants

☐ Presentation to participants or relevant community groups

☐ Other (Please specify below)

SECTION K: OTHER ETHICAL ISSUES

31. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?

N/A

SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS

32. Please check that the following documents are attached to your application.

☐ Letters of approval from any external ethical approval bodies (where relevant)

☐ Recruitment advertisement

☒ Participant information sheets (including easy-read where relevant)

☒ Consent forms (including easy-read where relevant)

☐ Assent form for children (where relevant)

☐ Letters of approval from locations for data collection

☒ Questionnaire

☒ Interview Schedule or topic guide

☐ Risk Assessment (where applicable)

☐ Overseas travel approval (where applicable)

34. Where it is not possible to attach the above materials, please provide an explanation below.