

**Exploring the meaning given by parents of children with special educational needs and disabilities in the early years to their interactions with practitioners**

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**Abstract**

This thesis applies a narrative methodology to explore the meaning parents of children with special educational needs and disabilities (SEND) in the early years give to their interactions with practitioners and considers the implications of the parents’ narratives in educational psychologists’ and other practitioners’ practice.

I review cultural narratives on parenting in Western societies which put parents in the ‘eye of the storm’, making them responsible for promoting their child’s development according to ‘normal’ standards, whilst societal factors are relatively neglected. In this context, parents' reports in research of stigmatising interactions with practitioners and others have not essentially changed over time despite their consistent calls to work collaboratively with practitioners (Green et al, 2013). In addition, important shortcomings of the needs-based approach to disability applied in the current SEND system (DfE, 2022) indicate that parents have not been listened to in order to improve their experiences. Parents of young children who are learning to coordinate their children’s care in this system might be the most affected. Alternative theoretical approaches to disability and child development are also discussed.

I use narrative interviewing to co-construct the stories of three parents of young children and I analyse the interviews by applying elements of Emerson and Frosh (2004) critical narrative analysis to highlight the influence of psychological and social narratives on the parents' stories. A complex tapestry of narratives unfolds in this analysis. I interpret that the parents involved in this study navigate self-blame and feelings of loss and joy which seem to be rooted in deep parental love. They appear to value having relationships of trust with practitioners who are able to contain emotions generated against a backdrop of dominant social discourses that emphasise their child's needs at the expense of their strengths and position parents as responsible for their differences. I conclude that these parents’ narratives support the need to broaden discourses around disability and child development in order to eradicate the oppression of parents, and in so doing promote emancipatory practice.

Key words: parents’ experiences, child development, disability, special educational needs, early years, Western culture, interactions with practitioners

*To my parents, in loving memory*

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**Abbreviations**

|  |  |
| --- | --- |
| ADHD | Attention Deficit Hyperactivity Disorder |
| CDS | Critical Disability Studies |
| CoP | Code of Practice |
| CQC | Care Quality Commission |
| CYP | Children and Young People |
| DCS | Disability Childhood Studies |
| DECP | Division of Educational and Child Psychology |
| DEdCPsy | Doctor of Education and Child Psychology |
| DfE | Department for Education |
| DSM V | Diagnostic and Statistical Manual of Mental Disorders (5th Edition) |
| DoH | Department of Health |
| EHCNA | Educational, Health and Care Needs Assessment |
| EHCP | Educational, Health and Care Plan |
| EP | Educational Psychologist |
| EY | Early Years |
| LI | Language Impairment |
| SALT | Speech and Language Therapist |
| SEED | Study of Early Education and Development |
| SEN | Special Educational Needs |
| SEND | Special Educational Needs and Disabilities |
| TEP | Trainee Educational Psychology |
| USA | United States of America |

**Positioning**

My interest in researching parents’ narratives on their interactions with practitioners who have been involved in their children’s lives is rooted in my prior experiences. Whilst working as a teacher and as a member of support staff in mainstream and specialist schools I was immersed in what I felt at the time were ambivalent approaches to educating children and working with their parents. On the one hand, there seemed to be an understanding that parents are key to helping their children do well at school, and school staff seemed to go to great lengths to organise parents’ evenings and events, and to use technology to communicate with parents. On the other hand, many teachers appeared strained and stressed because some parents were considered to be unreasonable, ‘hard to reach’, unaware of school rules and systems, or perceived to be overindulgent with their children. These parents might have had different explanations, and solutions, to the ones put forward by school staff in relation to situations in which their children found school life difficult. However, when I entered the teaching profession, problem solving collaboratively with parents seemed a hopeless prospect when I also felt the pressure of needing to deliver the curriculum combined with school expectations and rules being drummed into my ears. At that time, I think supervision would have been invaluable to reflect on my values and in whose interest I was working.

While working as a trainee educational psychologist I have been privileged to hear the narratives of parents who hope their children will be happy as they progress through their school years. Anguish is evident when this is not the case. These narratives resonate strongly with me, I think, because my younger brother had a difficult time at school. To me, he was my playmate and he was happy. However, in school he was viewed as lazy or having something wrong with him, which greatly worried my parents. This happened in Spain, my home country, so in my experience the issues presented in this research, situated in the UK, relate to Western countries generally.

Being a mother, and my previous profession, midwifery, have influenced my decision to situate this research in the EYs and to bring to the forefront the narratives of parents who might otherwise be unheard as they chart their new role parenting a child with special educational needs. Through the course of the research the notion of ‘Nothing About Us, Without Us’ is sustained. This concept has been used by the disability rights movement for years to highlight that full participation of people with disabilities can help shape a better world for all (Charlton, 1998). This is consistent with emancipatory psychology and a social-constructionist ontology, to which I will speak in detail in my methodology section. By entering the educational and child psychology profession, I aim to draw upon this ontological position to work in parents and their children’s best interests. I therefore hope to be able to listen to the parents' voice in this research to draw on its implications for practitioners’ practice, including EPs.

**Chapter 1. Literature review**

**1.1 Introduction**

This literature review explores research on current experiences of parenthood in Western countries prior to gradually focusing on the experiences of parents of children with SEND in the EY in England. It will then cast a critical lens over theory on child development, and the social constructs and narratives guiding current practice in the SEND system, in order to analyse their possible impact on the experiences of these parents. In this way, I aim to examine how cultural norms and values upheld in society are reflected in SEND statutory guidance for practitioners supporting children with SEND and their families. As a result of this review of the literature, it is proposed that researching the experiences of parents of children with SEND in the EY on their interactions with practitioners is needed for two reasons. Firstly, current research indicates that the support families receive from the current system is not good enough. Secondly, it feels important to investigate possible reasons why alternatives to traditional theories of child development and disability models that seem embedded in the current SEND statutory guidance are overlooked and consider whether these alternative narratives would be better suited when supporting parents of children with SEND in the EY. This would have implications for EPs, as they have the skills and knowledge to help to bolster the wellbeing of children and their families and calls to strengthen EPs’ involvement in the first two years of the child’s life are already being made (Division of Educational and Child Psychology (DECP), 2021).

In order to introduce current understanding of SEN and disability in the English SEND system, I refer to the SEND CoP (DfE/DoH, 2015). This makes use of the Equality Act 2010 definition of disability:

…a physical or mental impairment which has a long-term and substantial adverse effect on their [people with a disability] ability to carry out normal day-to-day activities (p 15).

and defines SEN as follows:

…a child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her (p 15).

The SEND CoP (DfE/ DoH, 2015) also clarifies that a child under compulsory school age has SEN if they are likely to fall within the above definition when they reach compulsory school age.

These definitions indicate that there might be an overlap between SEN and disability, but a child might have a disability without SEN. They also suggest the influence of the medical model of disability. Mitra (2017) describes the medical model as considering disability:

...a problem of the individual that is directly caused by a disease, an injury or other health conditions, and requires prevention interventions or medical care in the form of treatment and rehabilitation (p 20).

**1.2 Experiences of parenthood in Western culture**

Research on becoming a mother has described it as a major life transition where new relationships and roles are created and women engage in crucial psychological and social adjustments to successfully adapt to a new identity. This transition affects not only the mother, but her partner, other members of the family and wider society (McCourt, 2006). McCourt’s (2006) review of sociological research from the early 20th century until the 1950s on becoming a parent found that it has been envisaged as a potential crisis for married couples, although she warns that these studies are based on assumptions of a “...normal” family, which seems to relate to white, middle class parents living in Western countries” (p 51). Her review does not provide a definition of ‘normal’. Sanders et al (2022) interviewed 30 parents living in Australia as part of a grounded theory study and reported that new parents experienced parenthood as both rewarding and stressful. They were surprised at the frequency of parents’ reporting self-doubt, isolation and loneliness, which resulted from practical aspects of parenthood, such as lack of sleep, but also in many instances from social expectations (p 1879). These feelings and experiences might be shared by other parents raising their children in similar countries to Australia, where individualistic values are favoured over collectivist ones. It is worth noting that this study reported differences depending on individual and social characteristics, for example, the gender difference between mothers and fathers, with fathers taking a more relaxed approach to parenting. Sanders et al (2022) hypothesise that this could be either because the main carer was usually the mother so fathers had a lessened sense of responsibility for parental duties, or because they spent less time in public with their children and experienced less criticism, which might translate into increased confidence. They warn that gender differences are not a universal finding (p 1888).

I will now explore the social expectations of parenting in Western culture in order to position and gain a better understanding of research on experiences of parents of children with SEND.

**1.3 Constructing the perfect child**

Billington (2006b, p 67) describes growing up in the 1950s in England. At that time, the idea of a safe existence was promoted by an idyllic image of a father at work and a mother caring for the family. However, he pointedly acknowledges that this experience of safety within the family was not a reality for everybody, and depended greatly on social factors such as socioeconomic status. Sanders (2020) reviews the literature on parenting to argue that society nowadays maintains a focus on families and parents when looking for accountability for children’s poor outcomes. She concludes that, as a result, more systemic causes of adversity during childhood might be missed and the focus on individual families could therefore negatively affect the parent-infant relationship (Sanders, 2020).

Suissa (2006) illustrates this point by describing the barrage of advice parents are subjected to on how to parent “...healthy, happy, self-confident, intelligent children” (p 72). She concludes that, despite the contradictory advice on offer, parents are pressured to get involved in all aspects of their children’s lives while the quality of the parent-infant relationship might be neglected. According to Suissa (2006), parenting becomes a “doing” thing rather than emphasising the importance of being with the child and child and parent learning from each other (p 72). Sanders et al. (2022) explain that the tendency in the last few decades towards heightened financial and social concerns for children has resulted in the prevalence of intensive parenting styles, which are more demanding on parents and might affect their emotional well-being more intensively than previous parental frameworks.

Sanders et al (2023) focus on a related but different factor affecting parents’ wellbeing and adaptation to their new role: new parents’ idealistic expectations of parenthood. The parents in their sample, which was the same as the one used in Sanders et al (2022), reported “...unrealistic expectations, a lack of preparation, and recommended that parenting information be provided by professionals prenatally” (p 550). These researchers considered cross-cultural qualitative research that has noted the same result and put forward different explanations for these idealistic explanations, including representations of the family in the media and the concept of “Optimism Bias”, which was reviewed by Sanders et al, 2023, p 859. They explain that this refers to people forecasting more positive outcomes for themselves in comparison to average outcomes.

So how is this research relevant for parents’ experiences of parenting a child with SEND?

At the same time as voices proposing the need for alternatives to individualistic narratives of parenting in Western societies have been raised, alternatives to the dominant medical model of disability with its emphasis on within-child deficit have also been indicated. Goodley and Roets (2008) explain that the social model of disability

…has turned attention away from a preoccupation with people’s ‘impairments’ (and the associated ‘consequences’ on everyday activities) and instead focused on the ways in which disability is created through the social, economic, political, cultural, relational and psychological (p 241).

However, the lack of acknowledgement of impairment in this model has been fiercely contested. Shakespeare (2006) exemplifies this criticism. The biopsychosocial approach attempting to integrate biological, psychological and social factors does not seem to solve this problem because it might overemphasise medicalization (Shakespeare, 2006) and oversimplify the different factors influencing the experiences of disabled people (Goodley, 2017a). I think that applying the reflective pragmatic stand of social constructionism (Gergen 2022) embedded in this research to wonder whether the social model of disability is helpful might find that disability in this model is still perceived as deficit, therefore, the agency of disabled people to acquire a different identity to ‘being in need’ or ‘lacking’ might be hindered. I would argue that helpful approaches to disability need to take an account of the individual’s experience to understand the complexity of disability away from deficit.

An example of such approaches is Critical Disability Studies (CDS). This aims to provide an alternative to the deficit approach to disability (Curran & Runswick-Cole, 2014). Goodley (2017b) explains that CDS consist of a diversity of theoretical responses to factors leading to exclusion. Lewin’s aphorism ‘there is nothing as practical as a good theory’ can be applied in this case as CDS goes beyond theorical propositions. CDS draws practical implications by discussing the complexities of discrimination, including intersectionality, the deficit approach to disability in Western societies and different approaches to disability in different cultures (Goodley, 2017a, Goodley, 2017b). CDS has combined with Contemporary Children’s Studies, which questions the construction of ‘normal’ child development, leading to the conception of Childhood Disability Studies (CDS) (Goodley, 2017b). This approach to disability aims to overcome a deficit view of disability and child development and, as a result, it provides an understanding of children as having childhoods, not problems or being a problem (Curran & Runswick-Cole, 2014). This alternative perspective bolsters a human rights approach to disability, which advocates for every child’s right to develop and promotes equality and people’s agency through participation (Sayers, 2018). Perhaps these approaches can be applied in practice using Gergen’s (2022) transformative dialogue to generate shared understanding through human connection as opposed to expert-knowledge epistemologies.

The rest of this chapter explores research on the experiences of parents of children with SEND and ways in which different cultural narratives might influence them.

**1.4 Research on the experiences of parents of children with SEND and the possible implications for practitioners**

This literature search explores literature in the fields of psychology, sociology and midwifery. The databased used includes Octopus, PubMed, Star Plus and Google Scholar. Further information was obtained from DfE published documents. Relevant articles were also identified by looking through the reference list of the lecture on child development delivered to TEPs on the DEdCPsy at Sheffield University. I first situated the research by searching for literature on experiences of parenting in Western societies. Afterwards, I explored the literature on experiences of parents with children of SEND in the EY and different models of child development and disability.

Van Wyc and Leech (2016) reviewed 10 studies undertaken in Brazil, Belgium, USA and the UK to explore the challenges that mothers of children with disabilities experience in their transition to motherhood. They stated that women who give birth to children with disabilities are “vulnerable” (p 556) because while they adjust to more complex situations than other parents, they also develop the role of coordinators of their infants' care on top of forming a relationship with their infants and adjusting to their new identity. In relation to the research on parenting discussed above, this role seems to be a further social expectation, yet is one which might also negatively affect the mothers’ wellbeing.

A large proportion of the research on mothering a child with a disability focuses on grief around diagnosis, according to Brown (2013). Her study, based in Australia, used thematic analysis informed by a constructivist approach to analyse the data. Brown (2013) interviewed six mothers to explore the occurrence of grief as they mothered their children with intellectual impairments through to young adulthood. Her results suggest that each mother's relationship with their child was unique and that grief is an “...adaptive, dynamic and a circular process” (p 119) which evolves from being child focused to concentrating on family and society factors as parents gain mastery over the practicalities of the child’s needs and their expectations change. Brown (2013) proposes that personal and societal factors influence the frequency and intensity of the mothers’ grief response (p 119). For example, meeting milestones in the child’s different developmental trajectory was met with both joy and grief, when thinking of what other children are doing at different stages. Brown (2013) concluded that ongoing support and advocacy for mothers is crucial in order to facilitate access to services.

Bruce & Schultz (1996) interviewed 59 mothers and 59 fathers three times over a three year period and they reported that fathers and mothers grieve differently. Mothers reported more intense experiences of grief than fathers. The researchers hypothesised that this might be because, traditionally, mothers take the role of the main carer and they concluded that practitioners working with families need to create opportunities to help each partner understand the other’s grieving process (Bruce & Schultz, 1996). Research has also reported that stress and isolation associated with parenting children with SEND contributes to family breakdown rates being higher than in families who do not have children with SEND (Contact a Family, 2011, Holland, 2018). This research explores the experiences of mothers and fathers to be able to better understand both.

Green et al (2013) reviewed 78 qualitative studies published between 1960 and 2012 in different Western countries to explore how the experiences of parents of children with disabilities has changed over these decades. Remarkably, they found little change in some aspects of those experiences. In particular, they describe parents feeling powerless when they learn about their children’s diagnosis because disability is unknown to them, so they need information from practitioners. In addition, they enrol on a quest to find appropriate educational, therapeutic and care services. Green at al (2013) conclude:

The message that comes through loud and clear across decades and cultures is that parents want useful information and appropriate services for their children, favor partnership over professional dominance, want to be respected by professionals, and, most importantly, want their children with impairments to be viewed and treated as valuable human beings (p 162).

Green et al (2013) also described how family-centred approaches in practitioner training and practice were developed in the 1990s, so they reported with surprise that stigmatising interactions with unhelpful practitioners and others are still being reported by parents and have not essentially changed over time. However, there also seemed to be recognition that some perspectives had shifted, perhaps to account for changes in academic discourses on disability towards a more social model of disability. In the later studies, parents tended to question the value of the concept of ‘normal’. Goodley and Roets (2008) explain that the social model of disability moves the focus from impairment to the ways in which disability is created by environmental factors. As a result, I think that further research is needed to evaluate the application of newer academic discourses and narratives, which might potentially challenge the shortcomings of the medical model in practice.

Douglas et al (2022) help practitioners make sense of research on mothers’ experiences and find ways to support them by warning against applying a “stress and coping” model (Lazarus and Folkman, 1984, cited in Douglas et al, 2022). They postulate that in this model mothers’ two options in response to their child’s diagnosis of disability are grief or denial. This results in mothers who do not conform with the role of grieving mother being deemed unreasonable or “disordered” like their children. Douglas et al (2022) discuss that harm is inflicted by “a relentlessly disabling world” (p 6) to illustrate that parents learning that their child has a disability is not just one event. They conclude that in the Canadian and English educational systems parents must embrace a “sick role” (p 6) for their child in exchange for resources to support them. From their insiders’ view, as these authors are all mothers of young adults with a disability, as well as from their researchers’ perspectives, they are able to draw on alternative theoretical approaches to the medical model to liberate mothers from the narratives of madness and mental distress that seem imposed upon them when they advocate for their disabled children in their interactions with practitioners.

O’Connor et al (2021) used grounded theory methodology to analyse data from 19 interviews and 11 memoirs written by parents with children with developmental disabilities. From this data they designed a strength based framework to develop a service model to support parents to become “Confident Champions” (p 253), who foster motivation and hope while parenting their children. They proposed that championing skills consist of navigating unfamiliar services, developing advocacy skills and accessing information (O’Connor et al, 2021) and report the influence of within child factors and service factors to support parents to “adjust” to learning that their child has a disability. However, in contrast to previous research discussed in this literature review, this study does not report ways in which everyday interactions with practitioners and others influence parents’ experience. Instead, it focuses on a personal psychological process which can be supported by practitioners in a structured way. I think that not taking account of social interactions in this study might be evidence of different epistemological positions and models of disability and child development seen in research and practice.

**1.5 Evolution and evaluation of the SEND system in England**

This section discusses research on the effectiveness of the support provided to parents of children with SEND in England. The current English SEND system reflects a needs-based approach to SEND, which was formalised in the Warnock Report (DES, 1978) and focuses on identifying individual needs. Once these are identified, resources and funding can be accessed on behalf of the child. However, research has found that this approach might create conflict between practitioners and parents as it involves practitioners focusing on identification of deficiencies, creating an implicit narrative that the child is problematic (Russell, 2003, Green et al, 2013, Douglas 2022). This also feeds an ambivalent view of practitioners as experts that might not be conducive to collaborative working between parents and practitioners (Avdi et al, 2000). The key findings of a survey developed in 2011 by the charity Contact a Family involving 1148 responses of parents with disabled children across the United Kingdom were that over half of them felt isolated as a result of lack of support from statutory services such as social care and education. Not having the time or money to do things that other families do, and experiencing discrimination or stigma from family and friends, the local community, frontline practitioners, employers and complete strangers also contributed (CAF, 2011).

Russell (2003) writes from the perspective of being a mother of a child with SEND and also a practitioner working in early years. She proposes that supporting parents to explore, articulate and review their expectations of their child, their role as parents, SEND support services, and social and cultural values, might be more productive in supporting families than using a purely needs-based approach. Issues around power differentials impacting on how parents feel is embedded within the needs-based approach to SEND, and is illustrated in a recent interview by BBC News with Ivan Martin, the father of actor James Martin. Ivan spoke of how doctors told him that James would not be able to speak as a result of having Down Syndrome. He proudly reported that not only can James speak but he has won an Oscar (Murray, 2023).

A more collaborative approach with parents and between practitioners has been embraced in the principles of the current SEND Code of Practice (DfE/DoH, 2015). Therefore, I will also consider research on whether current legislation has improved support for parents of children with SEN.

Holland et al (2018) investigated how the introduction of the Children and Families Act (2014) had affected parental experiences by using a random sample of 240 parents of children with SEND who used the services of a charity in the Hull and East Riding area of Yorkshire. Participants had completed a questionnaire in 2008, a process that was repeated in 2017. The large number of participants, and using the questionnaire to compare answers on two different occasions, might be said to ameliorate the shortcomings of this methodology, for example changes in the sense that different participants might make of the same questions asked nine years later. In both surveys Holland et al (2018) reported a high percentage of unmet parents' emotional needs, particularly at certain points: when they noticed their initial concerns, if their children’s difficulties were unrecognised, during the diagnosis itself, and then in obtaining support. Despite their results indicating an increase in the number of families who are satisfied with the support they received after the Children and Families Act (2014) was introduced, 38% of parents (down from 50%) still said their experience was unsatisfactory. The researchers noted that a possible explanation is the increased scrutiny of parents, and mothers especially, that disempowers them and their family during, and after, any assessment process. They also suggested that practitioners might present a pessimistic outlook for the future (Holland et al, 2018) as illustrated above by James Martin.

If these assertions are correct, it would mean that the principle of collaborative working between practitioners and parents sought in the SEND CoP (DfE/DoH, 2015) is not always put into practice. Therefore, it is imperative that professionals reflect on power imbalances in their relationships with parents.

The Department for Education has recently reviewed the SEND system since 2014 and has identified three challenges (DfE, 2022):

1. Outcomes for children and young people with SEN or in alternative provision are poor.
2. Navigating the SEND system and alternative provision is not a positive experience for children, young people and their families.
3. Despite unprecedented investment, the system is not delivering value for money for children, young people and families.

The DfE consultation on their SEND Review Green Paper (DfE, 2022) proposes changes to the system in order to overcome these challenges. The DfE has focused on changing the way budgets are allocated, defining SEND more clearly at a national level and providing more training for teachers and SEND Coordinators (SENDCos). However, there does not seem to be a willingness to change the within-child deficit needs based approach to disability embedded in statutory guidance, even though to do so might bolster working collaboratively with parents to promote their wellbeing and positive interactions with practitioners (Russell, 2003).

It is usually the case that legislation represents the views of society at a given time and vice versa. Holland et al (2018) also investigated the support provided by family and friends and reported that one third of parents thought that family and friends did not understand their child and drifted away. Some parents also reported experiencing stigma generated by family and friends who refused to believe that there was a problem. Poignantly, parents also felt blamed by family and friends, practitioners and the wider society. Holland et al (2018) reported that it is unclear if it is the burden of care or the stigma perceived within families that cause negative outcomes for them. However, they concluded that it is evident that stigma creates additional stress on families. Johnson (2018) reports that families of children classified as having behaviour difficulties are particularly associated with views of poor parenting, so these parents experience a greater sense of blame and guilt from their interactions with practitioners compared with children with learning difficulties. Supporting this finding is the reflection in recent events of the shift in the way society perceives physical and learning impairment. For example, while watching the celebration of diversity and inclusion at the Birmingham 2022 Commonwealth Games, I felt overjoyed at the huge strides made towards endowing visibility and inspiration to people with physical impairments in the last 30 years. However, Wafula Strike (2022) articulates that there is a lot more to be done to improve opportunities and representation of these and other minority groups in sport. Research indicates that her view can be extrapolated to the world outside sport (Van Wyc and Leech, 2016, Green et al, 2013). Therefore, my research intends to explore the experiences of parents of children with SEND in any area.

The next section focuses on the experiences and support received by parents of children with SEN during the Early Years in particular.

**1.6 How well supported are parents of children with SEND in England during the Early Years?**

The SEND Code of Practice (DfE/ DoH, 2015) prioritises early identification of SEND in order that there can be early intervention. It states:

It is particularly important in the early years that there is no delay in making any necessary special educational provision. Delay at this stage can give rise to learning difficulty and subsequently to loss of self-esteem, frustration in learning and to behaviour difficulties (p 86).

The key questions are what is “necessary special educational provision” and how is it possible to ensure that it is delivered? During pregnancy and in the early years the SEND system relies on monitoring mainly by health professionals to identify SEND. However, it is debatable to what extent these practitioners have the capability to work in a coordinated manner while under considerable work demands (Frederickson and Cline, 2015, p 137). EY providers are also required to make arrangements to identify SEND using the Early Years Foundation Stage (EYFS) framework and the non-statutory Early Years outcomes. Frederickson and Cline (2015) evaluate this approach and conclude that assessment of SEND is particularly challenging when children are young and when a developmental condition is unclear, for example, language delay. They conclude that as in this system early intervention depends on early identification, it is inevitable that mistakes will be made (p 137). As a result, seeking early identification in this way might undermine parents’ confidence in practitioners and, as a result, the principle of collaborative working.

In order to explore the experiences of 16 children aged three to four with SEND on attending early years settings, Griggs et al (2017) undertook a qualitative study as part of the SEED sponsored by the DfE. The researchers interviewed parents and staff from the EY settings the children were attending. Their results indicate that settings complied with legislation and had assessment processes in place. However, they report that identification and diagnosis were not always straightforward. Nevertheless, communication between providers and parents was typically good, although it was reported that some parents did not engage with setting activities and these parents rarely requested that the staff make changes in the care they provided. The study reported that providers interpreted this was due to parents trusting that they knew what was best for their children (Griggs et al, 2017). However, this contrasts with other research pointing at parents feeling that they were the only or the best placed carers for their children (Van Wyk & Leech, 2016), so I would suggest that the factors behind the lack of engagement need further investigation. The study also reported that setting staff were satisfied with the level of care they provided, although they requested more funding, specialist support and specialist training.

The next section discusses literature on how alternative views of child development might be helpful in improving current practices.

**1.7 Alternative approaches to child developmental**

It has been discussed that current legislation on SEND relies on a traditional view of child development to guide practice. This view proposes that the child will go through different stages as they grow older and if they do not progress as expected they will be assessed for SEND as early as possible in order to enable intervention. The current SEND review taking place (DfE, 2022) acknowledges that this system is not sustainable financially and children’s outcomes and parents' satisfaction with the system are not good enough. Therefore, finding a way to overcome the shortcomings of this approach and improve outcomes for children and their families might involve not only appropriate funding, but also applying a different ontological and epistemological approach to child development.

Burman (2017) also articulates that child studies in the 19th century, which assume that normal development is rooted in biological principles, have shaped current developmental enquiry (p.19). In the meantime, research has made great efforts to find how a newborn becomes social. In the 1970s research focused on infants' innate competence to adapt to social situations. Burman (2017) notes that this research seems to have been interpreted in a one directional, dyadic way where mothers’ sensitivity shapes the child’s social awareness, for example, within attachment theory, which I will explore below. However, she argues that this interpretation is faulty, as it does not take into account the influence on mothers and their families of cultural definitions and contexts, for example socioeconomic background and the relationships infants form with people surrounding them other than the mother (Burman, 2017). Importantly, the narrative of SEND based on ideas of normal development might also be counterproductive as it could undermine the relationship between practitioners and parents (Russell, 2003).

The importance of an ecological approach in understanding the challenges facing parents of children with SEND is supported by the research on parents’ experiences discussed above, indicating that both personal and societal factors affect parents' stress (Brown, 2013, Holland et al, 2018, O’Connor et al, 2021). Totsika et al (2020) tested the Family Stress Model (FSM) in the families of 555 children with intellectual difficulties using a statistical approach involving structural equation models. The FSM proposes that economic deprivation affects child developmental outcomes through its effect on the parents’ emotional well-being and parenting behaviours. Therefore, these researchers hypothesise that parent-infant relationships are a mediator between early adversity and problem behaviours. Their findings indicate that early adversity (described as family poverty and maternal psychological distress at nine months) impacts both positive and negative dimensions of parenting in the early years. In addition, adversarial parenting (but not positive relationships) mediates the path between early adversity and problem behaviours at 7 and 11 years (Totsika et al, 2020).

As indicated, another psychological theory that has been cited to justify putting responsibility on parents for poor outcomes for children is Bowlby’s attachment theory (Burman, 2017). Attachment theory describes the relationship between an infant and their caregiver as the foundation for further healthy development of future relationships (Bowlby, 1969). Views on attachment theory have evolved to suggest that attachment is a systemic process where the effects of each part of the system influence each other. These elements would include parents’ characteristics, external factors and the infants’ temperament. In other words, this is not a process where only the parent shapes the infant (Dallos, 2006, p. 41). Patricia Crittenden’s Dynamic-Maturational Model of Attachment and Adaptation also offers a hopeful outlook on attachment theory by proposing that attachment can change from one context to another (Dallos, 2006). This is particularly relevant for school staff in understanding children who behave differently at home and in school, and the difficulty inherent in accessing the child’s emotional world because they have adapted to their environment well (Lyons, 2020).

A third body of research that might have been used to support a within-child view of SEND and point at parents as being solely responsible for their child’s development comes from neuroimaging studies. These studies investigate the structures and functions of the brain. They have boomed since the 1990s and large amounts of money have been dedicated to funding them (Rippon, 2019). Rippon (2019) warns that this is despite the methodology used in neuroimaging studies being rebuked by a lack of transparency on the limits of the technology involved. Billington (2017) discusses the inadequacy of portraying the brain as possessing predetermined, fixed characteristics which will determine a life-course because this perspective neglects people’s emotional worlds. Damasio (2000) proposes a possible explanation for the lack of evidence on the biological basis of developmental conditions (Timimi et al, 2011, Billington, 2017) by introducing affective neuroscience. He refutes the Cartesian idea of body and mind being separate identities (Damasio, 2000) and proposes a model in which emotions and thoughts are mediated by our interactions with the external world (Le Doux, 1999). Gerhardt’s (2004) review of neuroimaging studies concludes that brain development depends on lived experiences, even though she also emphasises the mother-infant relationship to achieve healthy brain development, neglecting other factors. Summarising, these authors argue that brain structure and function is interconnected with societal factors.

**1.8 Summary and research questions**

This critical literature review has identified the cultural discourses on parenting which might be influencing the experiences of parents of children with SEND and their expectations of parenthood. It describes the current within-child deficit-based approach to SEND embedded in statutory practice (DfE/DoH, 2015) ingrained in the process of identifying individual need to open access to resources, and research highlighting the shortcomings of this narrative. Particularly in the context of this research, such a narrative does not seem to be compatible with practitioners working collaboratively with parents despite research reporting that parents have been requesting this for decades (Green et al, 2013), leading to power differentials and conflict in their interactions.

It feels as though parents have been put in the ‘eye of the storm’ by cultural discourses in Western societies making them responsible for promoting their child’s development according to ‘normal’ standards, whilst societal factors have been relatively neglected. Alternative approaches to the within-child deficit approach and traditional theories on child development seem to offer an emancipatory perspective more conducive to practitioners and parents working collaboratively.

The focus of this study is particularly relevant in the Local Authority in which I am completing my placement as a trainee educational psychologist.The 2023 Ofsted and Care Quality Commission (CQC) area inspection of SEND services identified that an area requiring improvement is: “A lack of trust and faith in the local area’s work from too many parents and carers.” (Ofsted and CQC, 2023). Therefore, I feel that this research might offer recommendations to help to improve SEND services this specific LA might draw upon as well as have wider implications.

My research seeks to listen to parents' narratives to explore how the issues discussed might be affecting parents’ experiences of their interactions with practitioners. The following research questions have been identified:

* What meaning do parents of children with SEND in the EYs give to their interactions with practitioners working in the current SEND system?
* What do parents of children with SEND in the EY say happens within these interactions to enhance their wellbeing and support their children?
* What is the role of the EP in supporting parents of children with SEND in the EY and in supporting practitioners to learn from parents’ accounts of their mutual interactions?

**Chapter 2. Methodology**

**2.1 Overview**

Rather than viewing disability as a marker of lack we would want to ask what disability brings to the party in terms of rethinking pedagogical practices, reshaping educational spaces and revisioning the ideal goals of educational psychology practice. (Williams and Goodley, 2017, p 53)

In this chapter I discuss my ontological and epistemological positioning to justify the methodological and procedural decisions I have taken to answer my research questions. I will argue that using a narrative methodology located within a social con

structionist epistemology corresponds with my research aims of empowering parents of children with SEND in the current cultural and legislative context by giving them voice. I will also propose that narrative methodology is a form of emancipatory psychology because they are underpinned by the same values, for example, compassion, self-determination, diversity, collaboration and social justice (Prilleltensky, 1996). Prilleltensky (1996) described emancipatory psychology as supporting “people’s abilities to pursue their ends in life without oppressive restrictions” (p 307). Then, I will attend to the tools I have used to attain quality in the research and how ethics has been integral to this process.

**2.2 Ontology and epistemology. ‘Choosing’ social constructionism.**

In this study I aim to give voice to the parents of children with SEND in the EYs because my experience working in, and using, Western education systems has indicated to me that parents can be marginalised and disempowered by discourses and narratives prevalent in the current SEND system, which seem to reduce parents and their children to a position of being in ‘need’. This is also noted in research studies (Sewell, 2016, Russell, 2003) and theoretical arguments (Bhaskar & Danemark, 2006, Goodley & Roets, 2008, Douglas et al, 2022). Consequently, I have decided to use a qualitative methodology because it can give voice to those whose accounts might otherwise be discounted (Willig, 2013), therefore, providing insights into situations that might not be available to other methodologies.

By qualitative research I refer to an inductive approach concerned with the exploration of meanings to generate knowledge (Willig, 2013). I believe qualitative methodology supports me to answer my research questions best because I acknowledge that I am not a neutral observer in the research process; I bring to the research previous experiences that will inevitably influence my understanding. I also think that qualitative methodology is appropriate because, as Billington and Williams (2017) note, approaching research in this way, listening to CYP and their families’ own account of their experiences, can challenge previous knowledge based on theories and practices held as ‘truths’ and offer a better and richer understanding. In the context of this research, by adopting qualitative methodology and seeking to understand contextualised meaning in the narratives of parents of children with SEND, I hope there is the potential to promote emancipatory psychology in the form of more inclusive and equitable practice therefore improving parents’ and practitioners’ experiences and opportunities for collaboration.

I have grappled with different epistemological approaches before deciding upon social constructionism. I believe that the emancipatory objective of my research is compatible with a critical theory epistemology coined at the University of Frankfurt in the 1920s (Howell, 2013). The Frankfurt School postulates that collaborative working with “the oppressed" is necessary to accomplish social change, otherwise one authoritarian rule is simply replaced with another (Freire, 2018). This concept was summarised in James Charlton’s book through the motto “nothing about us without us” (Charlton, 1998) and has been used by disabled people’s organisations for years. This is the epistemological grounding for participatory research.

Howell (2013) explains that in participatory research change is brought about by sharing the ownership of the research with the participants, who analyse the research problem as co-researchers and take community action in accordance with the research conclusions. Although this epistemology is compatible with my research and its aims, time constraints and the limitations of the resources available to submit my doctoral thesis made it necessary to reject the participatory research paradigm in full. Instead, I have settled for striving to be transparent by discussing and justifying the decisions I have taken during the research process, and being reflexive by reflecting on how my own beliefs and practice have influenced the research and my interpretations. In so doing I hope to minimise power imbalances and prevent misrepresentations of my participants’ narratives. In other words, I am aware that not only the participant’s background and experiences will shape the research but also my own, for example, through my status as a researcher and practitioner.

The ontological position of critical theory is based on historical realism and postulates that there is a reality influenced by social and historical forces. In this research I intend to acknowledge and discuss these social and historical processes to privilege a wider range of voices than the most frequently heard in legislation and society. Bhaskar and Danemark (2006) persuasively argue that critical realism is characterised by “double inclusiveness” in the study of disability, meaning that it accommodates for the insights of other positions whilst avoiding their drawbacks, and it also allows the researcher to study how the relevant levels of reality determine each context. This means that reality becomes “multi-faceted” (Howell, 2013); the real world exists beyond the world the researcher can observe. Yet, as I reflect on my own stance, I believe that I cannot fully embrace a critical realist or historical realist position in this research because I believe that the concepts of disability and SEND are co-constructed and are therefore understood differently by different people, including myself as the researcher; I acknowledge that my interpretation of the narratives I hear will be unique. In addition, I would argue that co-constructing knowledge with parents might bring positive outcomes in practice, such as promoting positive interactions between parents and practitioners. In this sense this research might be considered to be action research because co-constructing the research conclusions could promote change that will last longer than the research process (Parker, 2004). As a result, in this research I adopt a social constructionist position, meaning that I embrace a relativist position and reject the existence of a universal, objective truth or reality.

Parker (1998) argues that researchers tend to advocate either realist or relativist approaches intensively. Social constructionism can be criticised not because it acknowledges the researcher’s subjectivity but because it defends that there is no ultimate truth. In other words, I might deconstruct a concept but not attempt to do something about it for fear of constructing another faulty concept (Burr, 1998). As a result, Burr explains that social constructionism has been accused of lacking a critical edge (p 19). However, Gergen (2009) proposes that the relativist stand of strong constructionism upholds criticality because it means that all views, statements and values ascertained by a community should be constantly questioned. He proposes that social constructionism acts as “reflective pragmatism” (Gergen, 2022, p 29) enabling the possibility of inquiring all “traditions”, including constructions seen as “true” or “good”.

Potter (1998) redefines relativism in an attempt to solve the relativist-realist quandary. He proposes that relativism is “a non-position” or “radical scepticism that provides the only way of challenging all truths” (Potter, 1998, p 27). As I understand it, this brings an alertness to ethical dilemmas which otherwise might not be considered because points of view are seen as truths. Gergen (1998) posits that a shared culture and history leads to an agreement on when to use relativism or realism. He advocates a relational ontology where realism and relativism find “a promising synthesis” through, “a new range of relational forms” between them (Gergen, 1998, p 155). I find Gergen’s position helpful in providing ways forward within a social constructionist perspective. As a result, I am taking a social constructionist position in this research as co-constructing reality with participants empowers parents to provide alternative narratives to more prevalent ones in society in relation to the SEND system. They can own their narrative, which corresponds with the emancipatory aim of the research. I also would like to clarify that I am using the term constructionism and not constructivism because participants and the researcher will be constructing meaning through language, which is an ‘artefact’ created by communities rather than individuals (Rob & Rob, 2018).

**2.3 Narrative Analysis**

**2.3.1 Why am I using narrative analysis in this research?**

In the previous section I posit that this research aims to give voice to the parents of children with SEND in the EY. There are different methodologies that aim to accomplish this (Willig, 2013), for example, Interpretative Phenomenological Analysis (IPA) is concerned with gaining a better understanding of human experiences and perceptions of that experience. I think I could have focussed the research solely on individuals’ experiences. However, I decided to use narrative analysis because it considers the meaning that is given to an experience by the person making sense of it within the context of other constructions of the same story, some of which might be more dominant (Riessman, 1993).

Studying the social construction of meaning can provide an insight into which narratives uphold power (Gergen, 2012). Foucault’s analysis of power proposes an indivisible relationship between power and knowledge (Foucault, 1980). He bases this observation in his studies of the 18th century. By then, power was already exerted by dominant knowledges shaping people’s lives and described as scientific and objective (Foucault, 1980). White and Epston, 1990, use the term “unitary knowledges” to describe these dominant discourses viewed as truths (White and Epston, 1990, p 19). Foucault (1980) proposes that modern society promotes social control by normalising our and others’ adherence to these dominant discourses. Narrative analysis can, instead, provide space for “subjugated knowledges” to be performed and heard, generating alternative stories and knowledge, therefore, leading to action and change (White and Epston, 1990, p 20). These subjugated knowledges or alternative stories are part of a person’s lived experience but fall outside the dominant stories about themselves and their interactions with others (White and Eptson, 1990). Social constructionism (and narrative analysis) questions unitary knowledges, otherwise viewed as truths, to be able to hear those alternative stories (Gergen, 2022, p 29).

Riessman (2008) proposes that there will be as many narratives as people interpreting them and that they are multi-layered. This reiterates the premise of discursive analysis that language is performative and the way it is structured does not happen by chance. Rogers (2007) describes discursive analysis as studying the way language shapes social beings, in other words, language constructs reality and people. Bruner (1991) suggests that why the story is told and the background knowledge of the listener and the storyteller are the bases for interpretation. As discussed above, my view of narratives is that they are representations of experience and performative. Within narrative research I understand that people give a version of their experience and this version might change with time or the situation in which they tell their story. Many factors will influence how the story-teller makes meaning of experience and expresses it in a narrative, including the co-construction of the story with the researcher. I have chosen a narrative analysis method because it acknowledges the relevance of language itself and its performative function (the narrator’s motivations) to uncover the meaning of experience for the narrator.

**2.3.2 Critical narrative analysis**

In this research I have adopted Emerson and Frosh’s (2004) critical narrative analysis as a means of undertaking psychosocial research in which the individual and society are intertwined, meaning that in order to understand people’s experiences in the social world, knowledge of their inner worlds is required, and vice versa (Hollway and Jefferson, 2000, p 4). Riessman (1993) explains that since Aristotle stated that narrative has a beginning, middle and end, many scholars identify that kind of sequencing within narratives. It could be sequencing in time, known as consequential (one event precipitates the next in the narrative) or thematic (the narrative is connected by themes instead of time). However, I believe that narrative analysis means more than sequencing. Bruner (1991) is helpful when he describes ten features of narrative research. I think his wider description below helps to sustain trustworthiness in the research because it acknowledges the influence of the context in the narrative and, therefore, its subjectivity and performativity, rather than seeing the narrative as a representation of reality:

sequence and consequence: events are selected, organised, connected and evaluated as meaningful for a particular audience, and hence the focus of analytic attention on how and why events are storied, not just simply the content to which language refers (Riessman & Quinney, 2005, p 394)

Mishler (1995) concludes that there are three types of narrative analysis. Critical narrative analysis focuses on two of them: textual coherence and structure, and narrative functions. Emerson & Frosh (2004) analysed the narrative generated in an interview with a boy who sexually abused other boys in order to illustrate how critical narrative analysis can generate “situated, partial and warrantable psychosocial knowledge” while safeguarding the agency of the storyteller in the context of breaches of dominant or canonical narratives, as a result, promoting accountability and moral identity in the research (Emerson and Frosh, 2004, p 17). In order to do this, they draw upon Gee (1991), to carry out a macro and micro analysis of the text that attends to the structure and functions of the narratives. Emerson & Frosh (2004) also use five hierarchical interpretative levels of linguistic structure and meaning, which are anchored in the micro and macro analysis of the narratives they are analysing. I believe that providing this deeper understanding of the narrative’s structure (how the narrative works) and functions (the work it does) privileges the voice of the storyteller because interpretation is secured in the narrative. Paying attention to linguistic structure privileges the teller’s meaning-making because this kind of analysis generates interpretative questions which rule out many answers, enabling a balance of these constraints with the pluralities of possible meanings (Emerson & Frosh, 2004, p 62). Using Riessman’s analogy with music, it slows down the composition to notice relations; it notes how language is used to construct stories and the teller themself (Riessman, 2008).

As Emerson and Frosh (2004) do, I have also based my analysis of the participant’s interviews on Gee’s method of narrative analysis (Gee, 1991) as adapted by Mishler (1997), who illustrates the relevance of paying attention to the interview dynamics and interactions to note the influence the researcher has on the account of a narrative which otherwise might solely be attributed to the storyteller.

Whilst analysing the narratives I have been mindful of the relationship between the narrative as a whole and its parts because, as Bruner (1991) deftly notes, “the parts of the narrative serve as functions of the narrative as a whole” and “the whole cannot be constructed without reference to such appropriate parts” (Bruner, p 8). However, although this is a comprehensive analysis of a narrative, I do not believe that it accounts for the “unsayable”, which “can be detected in negations, revisions, smokescreens (diverting attention to a safer place), and silences” (Rogers, 2007, ch 3), and contradictions in narratives. Emerson & Frosh (2004) place their analysis in the context of Lacanian ideas, hence the descriptor psychosocial, and I have opted to follow suit in order to provide a more meaningful and complete analysis.

**2.3.3 Lacan’s Symbolic Order and language**

I was cautious about applying psychoanalytic concepts in this research and I have steered away from using methods such as free association narrative interview (Hollway & Jefferson, 2000) because of the possibility that the master narrative within psychoanalytic principles may disempower, pathologise and essentialise participants’ stories by the researcher believing that they know the emotional logic of the story (Parker, 2004). This caution has led me to draw upon Lacan’s psychoanalytic ideas because he argues for a “social notion of the unconscious” encouraging a bottom-up interpretative strategy in contrast to an expert-led one (Emerson and Frosh, 2004).

Lacan proposes that the Symbolic Order or the Other, refers to culture, rules, norms and language, manifesting itself in the ruptures of speech expression (Lacan, 2006b, p 223). Parker (2005) explains that Lacan refers to Saussure’s postmodern schema of language of “signifiers” (words, sounds, images) which demonstrate content. According to Saussure, meaning is created by relationships between signs in language, which consist of signifiers and the signified (Saussure, 2011). However, his psychoanalytic theory does not aim to uncover the “signified”. Instead, it focuses on the way signifiers relate to each other when we express ourselves. According to Lacan, signifiers “slide in one another producing a chain of meanings beyond what was intended by the speaker” (Rogers, 2007, ch 3). Rogers (2007) proposes that this has implications for the idea of the self. These implications are defined in Lacan’s theory of the “mirror stage”, where it is proposed that an infant recognises themselves in a mirror, gaining a mental representation of ‘I’ as a whole. This representation of an ideal self is an illusion. It is through the introduction to language later on that we are able to relate to others and in this way shape the ego, our image of self (Lacan, 2006a, p 75-81).

To summarise, by analysing how signifiers relate to each other in a narrative, the researcher gains access to the Symbolic Order, which is the “other”, the origin of the storytellers’ unconscious, which is interdependent with our own sense of self. In this way Lacan provides a way forward to analyse the “unsayable” signified in the way the storyteller relates signifiers to another, preventing “ascriptivism” (Emerson and Frosh, 2004 p 87), in other words, claiming meaning in discourse without explanation for it in the text. I believe this is the researcher’s ethical duty as the “unsayable” in a narrative might be thus because it is “too terrifying, disgusting or traumatic” (Frosh, 2008, 37) and so needs careful interpretation by the researcher.

The rest of this section delves into Lacan’s concepts of unconscious and subject to understand how his psychoanalytic theory can help to promote the narrators’ agency in research while exploring their subjectivity and meaning making.

Lacan’s view on the unconscious is based on the idea that it is structured like a language (Lacan, 2006b). Ferdinand de Saussure’s work on the structure of language inspired Lacan but Lacan’s focus is on the relationships between signifiers instead of the relationship between signifier and signified (Rogers, 2007). Lacan’s clinical work took him to propose that meaning is produced in the way signifiers relate to each other in speech (Bailly, 2012). These relationships are flexible, meaning that they produce a “signifying chain” where the links between signifier and signified change as signifiers are spoken and heard (Rogers, 2007). The social and the unconscious are connected in these signifying chains. Bailly (2012) explains that the Symbolic order can be accessed by listening to the different meanings created in the sliding of signifiers both in the conscious and unconscious. Lacan (2006a) proposes that the unconscious is symbolic and the acquisition of language in the mirror stage marks the creation of the unconscious when a child represses a thought which might be terrifying for them. Signifiers is what is being repressed, hence, the Other can be considered to be language itself. This might explain Lacan’s definition of the unconscious as the Other’s discourse (Lacan, 2006c). It needs to be noted that the unpleasant emotion attached to the signifier cannot be repressed, which might lead to displacement (Bailly, 2012). In addition to this big “Other”, Lacan (2006a) proposes that the social also influences an individual’s idea of self during the mirror stage through the signifiers exerted by others, for example, the child’s parents conveying that the child is clever.

Lacan (2006b) describes how to explore the relationship between the unconscious and the social. He states that “… [a double meaning] teaches us to follow the ascending ramification of the symbolic lineage in the text of the patient’s free associations” (p 222-3). This indicates that the unconscious lies in the disruptions of language and in the ambiguities and contradictions of what is being said (Rogers, 2007, Bailly, 2012). Analysing these disruptions and contradictions reflects Frosh’s invitation to speak from the margins to consider power imbalances between narratives and individuals (Frosh, 2010). In this thesis I have analysed the disruptions and contradictions in the narrative interviews with my participants to privilege marginalised voices. This has helped me to interpret and understand the meaning making and subjectivity of the narrators. In this way, I have been able to explore the narrators’ identities represented as Lacanian subjects. These are fragmented subjects shaped by language and the Other, as opposed to unified truths. Before delving further into how the Lacanian subject can be understood, I will discuss the controversies of applying psychoanalytical theory to explore subjectivity and how psychosocial epistemology as proposed in Lacan’s psychoanalytic theory can provide a way forward to solve them.

Applying Lacanian discourse analysis in this research has been helpful to address the dilemmas identified in the literature when psychoanalytic theory is used outside of the context of therapy in the clinic. Frosh (2010) discusses the two main controversies related to the application of psychoanalysis in social research. On the one hand, its top-down expert knowledge claims and, on the other, the divide between “external” social elements and “internal” psychological ones. Different psychoanalytic theories have emphasised this divide resulting in Parker (2004) articulating that:

Psychoanalytic subjectivity – our sense of ourselves as having hidden childhood desires and destructive wishes – is the perfect complement to economic exploitation in capitalist society, for both succeed in making the victims blame themselves” (p 105).

Lacan’s discourse analysis moves subjectivity from individuals to social relationships. According to Parker (2004), this can transform research into an emancipatory force. Exploring the unconscious by exploring the margins serves to disrupt these surface readings of division and “sutures” social and psychological elements as all contribute to the human subject (Frosh, 2010). Rustin (2019) acknowledges a different aspect of psychoanalysis which brings social and psychological together: the study of emotions. He welcomes observation methods moving from merely observing what is happening to acknowledging the observant’s subjectivity. As a result, I have viewed the interviews as insightful conversations and considered the way the parents made me feel. In addition, reflexivity has helped me to reflect on my role and biases in the research.

Another reason to apply psychosocial epistemology as embedded in Lacan’s psychoanalytic work is to avoid the “transparent self problem” enunciated by Hollway and Jefferson (2000, p 3). This phenomenon consists of assuming that individuals “tell it as it is” in their narratives. This is problematic because it ignores the complexities of narrators telling about themselves and the lack of direct access to another’s experience. As a result, Riessman (1993) articulates that interpretation in narrative analysis is unavoidable. In addition, the view of “telling it as it is” does not consider the influence of the performative function of narratives. According to Lacan, the narrators talking to an audience is another function of the Other in speech (Parker, 2005, Frosh, 2010). Frosh (2010) proposes that applying psychoanalytic theory outside therapeutic contexts can disrupt and challenge social norms and personal identities to “open up the narratives” by considering unconscious, marginalised narratives. This is how Lacan’s psychoanalytic theory has been applied in this research, as a method of undoing rigid identities and binary thinking (psychological/ social).

Fink (1995) notes that Lacan’s subject is an assumption but he interprets it is it’s own fragmented nature. He proposes that the Lacanian subject is a split, for example, between the ego and the unconscious. The ego has been forged in the mirror stage within the Imaginary order through the signifiers of others, for example, you are a good boy! It provides a unified sense of self but it contains misinterpretations and false images. Fink (1995) proposes that the subject transcends “being” because Lacan views the unconscious as the “agent of interest” and the ego as a distraction. The unconscious shifts the subject to the Symbolic order, to the discourse of the Other. However, this does not account for Lacan’s subject (Fink, 1995). The subject only appears in the chain of signifiers.

Bailly (2012) also discusses how the Lacanian subject can be interpreted in speech. He states that “master signifiers are the backbone of the human subject” (p 61). He describes master signifiers as a “linguistic tick” (p 61), meaning that are repeated in the narrative but when analysed might not make sense to a listener. These master signifiers might protect the ego by:

...redirecting signifiers in a painful signifying chain to the speaker in such a way that a signifying chain with the opposite, bearable, or even comforting meaning emerges in the conscious speech (Bailly, 2012, p 63).

However, the unconscious cannot be controlled by the individual so the repressed meaning will be present in the narrative, even though obfuscated. This supports the idea that narratives cannot be taken at face value and the need to analyse psychological and social factors in narratives gathered in research.

**2.4 Quality in qualitative research**

Reliability and validity are not appropriate terms when evaluating qualitative research as they would be for quantitative research. Rather, I intend to justify the concepts I have used to evaluate the quality of this research: reflexivity and trustworthiness. Howell (2013) explains that credibility, transferability and confirmability promote trustworthiness. Credibility can be assessed in the presentation of evidence on my interpretations. In order to promote this, I have anchored the conclusions of my analysis to the parents’ stories by providing examples from the transcripts throughout. Transferability can be enabled by recording data collection procedures, analysis and transcripts (Howell, 2013). I have made my recordings available to the reader and I believe the research conclusions might be helpful to other parents and practitioners. However, as I discuss below, the participants’ narratives and my conclusions about them are subjective and not generalisable to a wider population. Finally, confirmability refers to how my interpretations are founded in the parents’ narrative (Howell, 2013). Therefore, I have reported my relationships with participants and the research setting and I have included my analysis of the transcript of the narratives in the appendices.

Some researchers have posited the concept of coherence in their criteria to evaluate qualitative research (Elliot et al, 1999, Yardley, 2000). In this research I have looked for coherence between the research questions, my epistemological position and the methodology and methods I have used. Also, in order to maintain coherence between theory and my social constructionist epistemological position, I have aimed to be open to different theoretical underpinnings during the research process. There is a possibility that this openness might burden coherence in my interpretation of the stories I hear, which could be counterintuitive but reasonable. To illustrate this point, Riessman (2008) asserts that “consistency in a life story might be illusory” and identifying and acknowledging points of diversion within and between narratives might instead increase trustworthiness of the research.

**2.4.1 Generalisation and transferability**

Silverman (2013) states that “…unless you can show your audience the procedures you used to ensure that your methods were reliable and your conclusions valid, there is little point in aiming to conclude a research dissertation” (p 209). I agree with him in that qualitative research needs to address quality issues, not only to complete a dissertation, but to avoid producing self-serving knowledge which might be harmful to others. In other words, quality in qualitative research and ethics are intertwined (Chase, 2011). However, it is also widely accepted that the traditional measures of quality in quantitative research, reliability and validity, are not suitable to evaluate the quality of qualitative research (Yardley, 2000, Riessman, 2008, Willig, 2013). This is because qualitative research does not aim to generalise findings.

My aim in this research is to explore the participant’s meaning-making of their interactions with practitioners when having a child with SEND in the EYs. Findings cannot be generalised to the whole population or settings because the narratives in this research have been co-constructed and influenced by the participants’ and my subjectivity. I have used reflexivity to acknowledge that I am part of the research context, in particular, I am a practitioner influenced by my reading on the literature available on disability. I think reflexivity helps to produce insight into the decisions I took during the research process but it can only be partial (Howell, 2013). Therefore, I have welcomed supervision as a needed safeguard towards promoting reflexivity. Using Willig’s (2008) metaphor I accept the role of researcher as the builder of a house (p 13). I will use the narratives to build my interpretations but there will be other possible interpretations of which I might not be aware. Equally, while exploring meaning-making, dominant narratives might be challenged and discounted and others may come to the fore, which might be helpful for other parents and practitioners in other contexts. In this way I believe my research is, at least in part, transferable.

**2.4.2 Trustworthiness**

Riessman (2008) agrees that reliability and validity are not appropriate ways of considering the depth and breadth of the information gathered in narrative analysis. Howell (2013) posits that qualitative analysis should address trustworthiness instead of validity. This resonates particularly with narrative analysis because, as Bruner (1991) postulates, even though we may call narratives true or false they cannot be empirically verified, they are judged by their verisimilitude. Narratives are the “way we organise our experience and memory of human happenings” (Bruner, 1991, p 4). In this way they create an alternative reality which can be helpful to understand how human interactions are constructed (Bruner, 1991).

Howell (2013) notes that increasing research credibility could be achieved by providing “thick descriptions” which are translated into “thick interpretations” to satisfy others that conclusions drawn in the research are valid (p 190). In this research I have tried to provide “thick descriptions” by answering the questions posed by Riessman (2008): “what definition of narrative are you working with? To what extent are you paying attention to narrative form of language, local context and production, and broader social discourses? What are the epistemological and theoretical perspectives that frame your project?” (Riessman, 2008, p 200).

Blumenfeld-Jones (1995) proposes that respecting the participants’ intentions when telling the narrative also promotes trustworthiness. Possible ways in which I could achieve this have been to use Gee’s micro and macro analysis, paying attention to how the narrative is said and the context of the interview to privilege the participant’s meaning making. Frosh (2008) goes further and suggests leaving the narrative “open, provisional and uncertain” (p 38) to avoid exerting the power of an expert’s position over the narrative, which becomes a telling of “a better story about the subject than he or she can tell.” (p 38). In this research I have aimed at widening the hypothesis practitioners might be able to work with by listening to the parents’ stories.

**2.5 Ethical considerations**

In this research I follow ethical guidelines set out by the British Psychological Society code of ethics (BPS, 2004). The research has passed the Ethics Policy and Ethics Review Procedure at the University of Sheffield, which has been designed to safeguard participants’ safety and wellbeing by providing informed consent, confidentiality, responsible handling of the data and ensuring that the research is of value (University of Sheffield, 2021). Bennet (2016) describes ethical codes and practice guidelines as useful and necessary. However, I do not believe they are enough to practise ethically and promote participants' well-being. This is because of the imbalance of power in the relationship between participants and researchers and potential for abuse of participants’ rights, “which could find justification in the absence of self-reflection and supervision” (Bennet, 2016, p 86). Bennet also warns that codes of practice might encourage unethical behaviour if they are used as a checklist to exert defensive practice and replace self-awareness of moral values. As a result, and as discussed above, I have attempted to embed moral values by maintaining transparency, reflexivity and promoting participants’ agency in this research process in order to accomplish the emancipatory aim I have set for this research of empowering marginalised voices.

**2.6 Summary**

To summarise, in order to promote trustworthiness in this research I acknowledge that the analysis I have completed is one possible interpretation of the narratives meant by the narrators. This is because subjectivity is inherent in the narratives told. These narratives are performative, they function to persuade and the narrators positions are constructed as the narrative is told (Emerson and Frosh, 2004). In addition, they are co-constructed and interpreted by me as research and they will also be interpreted by the reader (Riessman, 1993). As a result, I have considered my interactions with the narrator by adopting narrative analysis as proposed by Mishler (1997). I have also aimed to privilege the narrators’ meaning making by using Gee’s (1991) micro and macro analysis to look at the structure and functions of the narratives and anchor my interpretations in the narratives, therefore, avoiding listening to them only for content or to confirm theory (Riessman, 1993).

In addition, I have drawn upon Lacan’s work to analyse “what is not said” and to seek access to the social using a bottom-up approach without imposing my views on the narratives. Lacan posits that the social is the origin of the narrators’ unconscious and interdependent with our sense of self. It can be studied by looking at the way signifiers relate to each other because these relations create meaning that the narrators might not have intended (Lacan, 2006b). As a result, I have problematised narrators to explore the connection between their narratives and identities by attending to their responses to events and people in the social world. This corresponds well with my understanding of people as psychosocial. In other words, simultaneously influenced by psychic and social discourses (Hollway and Jefferson, 2000).

**Chapter 3. Process**

**3.1 Overview**

In this chapter I describe and reflect on the way I applied the methods I used to recruit participants, plan and conduct the narrative interviews, and transcribe and analyse the data. It felt natural to me to consider these processes in a separate chapter as I view them to be tools I have used to apply the ontological, epistemological and ethical standpoints I described in the methodology. By describing the methods I used and reflecting on my positioning as a researcher I aim to increase the trustworthiness and transparency of my research.

**3.2 Ethics Approval**

To ensure that it follows the ethical guidance stipulated by the British Psychology Society (BPS, 2021) and the Health and Care Professions Council (HCPC), this research project was approved by the University of Sheffield Ethics Committee (see Appendix 1). I asked participants to sign a consent form specifying the data protection rules that would be applied and their right to withdraw (see Appendix 2), also providing an information sheet for participants to read before the interview (see Appendix 3).

In this research I have kept the anonymity of parents by using pseudonyms for parents and their children, and practitioners and services, to avoid identification. I think this protects the parents’ identity and also improves the research’ credibility because parents might feel more secure sharing sensitive information knowing that their stories are anonymous.

**3.3 Sampling**

I used volunteer sampling to recruit my participants. I recruited participants attending different groups for parents and children with special needs in the local area in which I am on placement as a trainee educational psychologist. These groups were organised by a charity for which I was volunteering. However, I did not recruit parents I had met in my volunteering role to ensure parents did not feel coerced into participating. An EP working in the same educational psychology service also recruited one of the participants from her caseload.

In order to recruit participants I had created a research poster (see Appendix 4) which I took with me to the parents’ groups. The EP who recruited one of the participants used the poster to inform about the research aims, criteria to participate and commitments required without putting pressure on the parent.

The inclusion criteria for participants consisted of parents who:

* Have children with SEND aged between 0 and 5 years old.
* Have been in contact with practitioners before, during or after their child’s SEND was identified.

Wells (2011) notes that the depth of the data analysis is one of the determining factors of the number of participants a research project will require. Therefore, I felt that balancing the depth of analysis a critical narrative approach requires and the short timeframe of this research justified using a small sample to fulfil its purpose, transferring “theoretical propositions” instead of generalising statistical findings to the general population. Riessman (2008) also justifies the validity of small samples because narrative-analysis is case-centred, an approach that has greatly contributed to current knowledge in social science and also clinical practice in medicine. As a result, I stopped the recruitment process after I had recruited three participants.

I am also aware that I recruited participants in a very specific context and this is acknowledged as one of the limitations of this research because parents living in different locations did not have the opportunity to join the research to talk about their experiences. Once again, time constraints limited my capability to extend the recruiting process to different counties. The literature has highlighted that participants’ social characteristics might influence their experiences (Crenshaw, 1998, Vertovec, 2022). In this study, I was able to recruit two fathers and a mother. I did not record their socioeconomic background or other social factors and as a result I was not able to analyse how this might have influenced their interactions with practitioners. Nevertheless, opening the research to all socio-economic backgrounds gave a broader sample of parents the opportunity to participate.

*3.3.1 Who are the parents participating in the research?*

The parents’ pseudonyms in the research are John, Kate and David.

*John*

John is stay-at-home dad while his wife works as a carer. He was diagnosed with several developmental conditions as a child and when we first talked he told me that he could draw on how interactions with practitioners have changed in time, which he did in our interview. John’s daughter, Maddie, has a diagnosis of autism and sensory differences. Staff in the nursery she attends since she was about seven months have started the EHCNA process. John and his wife also take Maddie to playgroups for families of children in the EYs with SEND once a week. John explained that going to nursery has been beneficial to help Maddie communicate with others.

26. and she’s come on leaps and bounds in there. Absolutely loads!

*Kate*

Kate is the only working parent in the sample. Lee, Kate’s son, is currently going through the process of being diagnosed with autism and obtaining an EHCP. Kate also takes Lee to playgroups. Lee attends nursery because the SALT recommended it and, although Kate had not planned to take him to nursery, she is pleased he started attending.

114. And he has been there now since/ he's done a full year at nursery

115. and there's been no change in his speech.

116. Oh, ye, socialising/ it does seem to have come on

117. and (.) I am glad that we did send him to nursery/ because he struggled at first/ but now he loves it/ he loves going

In the same way as John’s daughter and David’s son, Lee has one more academic year to complete in nursery before starting school.

*David*

David was recruited by one of the EPs I work with. He is his children’s main carer while his wife works. The family has recently moved houses so David is decorating it, which seems to add to his responsibilities. He states “I still have half a house to build (.)” (line 319). Currently, Rob is going through the EHCNA process and the paediatricians have diagnosed him with hypermobility. David and his wife have recently started taking Rob to the same playgroups as John and Kate and they have also attended groups with the SALT. Rob attends the nursery in his older brother’s school and David appreciates knowing the staff there.

**3.4 Pilot**

Before conducting the narrative interviews I was keen to test my own interview technique to be able to generate meaningful data and also try out whether my recording devices would work well. A fellow trainee educational psychologist who has a daughter with a disability kindly offered to take the role of the participant in a pilot interview. This gave me the confidence that introducing the first question worked to elicit narratives. I asked:

Can you tell me about your interactions with practitioners who have been involved in your child’s care or education, for example, nursery nurses, doctors, EPs, etcetera?

I had planned to expand with follow up questions, such as “tell me more” but found that on most occasions I was able to incite the conversation with a comment or question that arose naturally based on aspects of what I was being told I thought could be explored further. I had prepared further questions in case my introductory question would not generate a story but I found that I did not need to ask them. I was aware that my fellow trainee wanted to help me and this might have facilitated the process of generating the narratives. We already shared a relationship so rapport building was minimal. However, completing the pilot interview helped me to trust the process of co-constructing the narrative. Transferring the sound files to a computer was also straightforward and the sound was good.

**3.5 Narrative interviews**

I emailed each of the parents who had expressed an interest in the research the consent form and information sheet, and we discussed their right to withdraw and confidentiality before they signed them and the interviews took place.

In the planning of the interviews I communicated the contact details of helplines, including counselling services offered by the local charity organising the groups the parents attended, in order to promote their wellbeing. None of the parents indicated that they would make use of these services. However, the conversations were emotional at times so I strove to provide containment by showing understanding and empathy in the moment.

I met two of the parents in a Children’s Centre managed by the organisation I volunteer for, which also organised the groups the parents attend. A third parent wished to meet with me online so I respected her preference to facilitate her participation in a way that was comfortable for the parent and promoted her agency to make decisions about her contribution to the research.

I was keen to conduct the meetings in a relaxed atmosphere and I took snacks to the face to face interviews. I followed the framework I have described in the previous section to complete the interviews and viewed them as a conversation (Riessman, 2008). I felt that the opening and follow up questions worked well in generating detailed narratives. The follow up questions I used arose from the parents’ answers and I was also able to ask about services that I thought they might have had access to, if they were not mentioned first by the participants. I think it was helpful that I have always found facilitating consultations a satisfying professional role and I wished to approach the interviews with similar genuine curiosity.

**3.6 Reflections**

I did not feel the need to take notes during the interviews as I was going to listen to the recordings, but I did take notes on my reflections afterwards. Within this research reflexivity has helped me to identify ways in which I might have influenced the research process. I have mostly done this within the text because I feel that my reflections are an integral part of this research. However, I have also used reflection boxes where I felt that examination of my feelings and thoughts was pertinent.

|  |
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| Reflections  Some of the reflections I noted after the interview included wonders/ doubts about whether I had asked the “correct” questions and been able to gather meaningful information. I conclude that asking more direct questions than the ones I used might have been intrusive and would risk being patronising. On the other hand, I felt I might have led the conversation by interfering with a comment or question when parents were talking. Afterwards, while transcribing and analysing the data, I confirmed that this had happened at times. I think it is a learning point for me. However, I think I made these comments as I would have made them in a colloquial conversation and this helped the interview feel relaxed and conversational.  At times during the interviews the parents' feelings of guilt provoked empathy and strong emotional reactions in me. For example, when Kate told me that she would parent differently if Lee was diagnosed, when John got upset because he blamed himself for his daughter's disability, and when David expressed his frustration at not being able to understand his son’s needs and wants. I think my emotions hearing these narratives have influenced the way I reacted to them in the interview, which corroborates their co-constructed nature. |

**3.7 Transcript analysis**

*3.7.1 Introduction*

In the previous chapter I justified why I decided to analyse the parents' narratives using critical narrative analysis, which takes a psychosocial perspective of narrators and argues for an analysis of the structure and functions of language. In order to do this I applied Gee’s (1991) linguistic approach to narrative while considering my influence in co-constructing the narratives as proposed by Mishler (1997). I also drew upon Lacanian concepts to analyse “the unsayable”, the meaning which narrators might not be able to put into words (Emerson & Frosh, 2004). In this section I am going to describe how I have undertaken this analysis.

Before I started the micro and macro analysis I transcribed the narratives by hand by carefully listening to them. The platform I used to undertake the online interview provided a transcript. However, I still needed to go through it carefully to ensure the correct words had been transcribed.

*3.7.2 Micro-analysis*

I based this aspect of the analysis on Gee’s (1991) linguistic approach to narrative. This method bases the structure of the text on the stress the narrator puts into different words. I formed “idea units”, described as a group of words carrying a single piece of information, by identifying the words stressed by the narrator's intonation, called pitch glide. Then, I grouped the idea units into lines. Gee (1991) explains that a line is the equivalent to a sentence in writing, it revolves around a central idea. This constitutes the micro-analysis of the text and it took many times listening to the recordings to complete it. As an example, in John’s assertion after Maddie is diagnosed with autism and sensory differences:

46. (1) it was kind of (.) I kind of (.) I said to you (.) it was kind of a relief

“relief” is the pitch glide because he put emphasis on this word. However, I also wondered why he hesitated to articulate this idea unit. I needed to keep listening and undertake the process of macro-analysis to be able to interpret what John meant by “relief”.

I have used a reduced selection of Jefferson’s (2004) conventions as well as Gee’s (1991) while transcribing the interviews to help display how the narrative was co-constructed in the interviews:

|  |  |
| --- | --- |
| **Symbol** | **Description** |
| (.) | Pause less than a second |
| (2) | Pause length in seconds |
| (laugh) | Non-verbal communication |
| [] | Speech overlaps |
| (???) | Unable to determine speech in recording |
| italics | Emphasis placed on the word |
| / | Change of tone to signify new idea unit |
| 1 | Idea units grouped in lines |

*3.7.3 Macro-analysis*

I continued listening to the recordings to organise the transcript into stanzas as the basic building blocks of the discourse’s structure. Gee (1991) explains that each stanza is a single ‘vignette’ and moving on to the next stanza represents a shift in perspective marked by different linguistic devices. I grouped the stanzas into larger units: strophes and parts, which form the story as a whole. This process was highly subjective. I applied Gee’s guidance loosely because I found it difficult to decide when to start and finish the different sections. Riessman (2008) and Emerson and Frosh (2004) also note the subjectivity within this process. In contrast to Gee (1991), I have included my interventions in the interview to acknowledge that the narratives were co-constructed at that stage (Mishler, 1997). I have also used a reflexive approach to the analysis by including hesitations and speech disfluencies instead of cleaning them in the text.

I reflected on the different possible ways I could have undertaken the analysis and opted for the approaches described to try to privilege the narrators’ voices at all times. I have included the micro and macro analysis of the transcripts in Appendix 5, 6 and 7 to add trustworthiness to this process. Once I had organised the narratives in stanzas, strophes and parts, I put their titles together without the transcript to gain a better understanding of the narratives emerging in the analysis (see Appendix 8).

Within my analysis I have also applied aspects of Lacanian psychoanalysis (Lacan, 2006a, 2006b). This was helpful because I was able to reflect on the unsayable: thoughts or feelings the narrators might have found difficult to express with words (Rogers, 2007, p 99). I felt that this was required to have a more complete understanding of the narratives. This also assumes the perspective that people are psychosocial beings, which is embedded in this research. Therefore, I reflected on the individual and social factors influencing the words and also the contradictions, hesitations and omissions presented in the narratives.

Returning to John’s transcript to explain the meaning of relief:

**Strophe 6**: feelings about diagnosis

**Stanza 12**: a relief to have an explanation for others

46. (1) it was kind of (.) I kind of (.) I said to you (.) it was kind of a relief.

47. I know she is not/ (1) cause people look at her cause she has kick offs in like town and everything

48. (.) and people just stare.

49. Then (.) they don’t know to say something to you or not and then some people say to us (.) what’s up?/ I said “I don’t know”/ but now I can say.

**Stanza 13**: a diagnosis is more than a label

50. Someone told me the other day: is there anything…?/ Does she have disabilities?

51. Now I can say yea/ she’s autistic and sensory needs so

52. (.) that’s kind of (1) it’s like a label but it’s not, it’s more.

53. There is a diagnosis of why she’s like she is/. She is not just a naughty child.

54. She is (.) there is something mentally wrong with her.

I have interpreted that John means that a diagnosis is a relief because it is an explanation for others. “Relief” seems to be a “master signifier” supported by the dominant medical model of disability. It might have the function of protecting John’s ego but as signifiers slide on each other, his narrative portrays a different subject that sees a diagnosis as something different to “relief”. It is an acknowledgement that there is something wrong with Maddie.

**3.8 Giving the narratives back**

I felt privileged listening to these parents' experiences and indebted to them. I thought that it was important to make them aware that I had an understanding of what they had told me. When the interviews finished I asked the parents if I could contact them again after analysing the narratives in order to gather their feedback on the analysis. I wanted them to know that sharing their experiences had been worth it.

It took me months to analyse the data. Finally, I emailed parents with summaries of the narrative analysis I undertook (see Appendix 9) and offered an opportunity for them to meet or talk about them on the phone. I talked with two of the parents on the phone and with another on a video call. These were short conversations. Two of the parents said that the summaries were fine and they were happy with them, one said he had not received theirs. I sent it again to the same email address and I did not hear back from the parent. I did not chase this feedback further because on reflection I felt that sharing the summaries of the narratives was not really helpful for the parents, or the research.

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| Reflection  I feel that asking the parents for their opinions on the summary of their narratives might have been tokenistic because I did not share my perceptions on the cultural discourses I thought were affecting the narratives, which might have hindered an open and equal discussion. In addition, I think these parents might have wanted to help me by giving positive comments to the summaries.  I think that asking for feedback in a more meaningful way might have required entering the cycle of planning, action, reflection and evaluation used in participatory action research. However, this was not possible due to the research time frame. I feel this might have been a missed opportunity to work with the parents to (perhaps) build new meanings around their interactions with practitioners during their child’s early years. In the future, I think action research would address this shortcoming. |

**Chapter 4. John, Kate and David’s narratives**

**4.1 Overview**

In this chapter I offer my interpretation of the narratives I have identified through a reflective process to determine stanzas, strophes and parts as detailed in the previous chapter. This analysis includes my own performance and starts discussing the influence of each parents’ psyche and social narratives. These influences are more explicitly related to the research questions in the discussion.

In this process of reflection and interpretation I have found it particularly helpful to apply psychoanalytic concepts such as containment and a holding environment. The concept of containment was developed by Wilfred Bion, who drew attention to an infants’ overwhelming feeling being recognised by a good enough carer who is able to make them feel understood and secure (Bion, 2018). Williams (2013) proposes that, according to Bion’s theory, talk by professional practitioners has the potential to contain and helps to regulate emotions leading to the formation of knowledge and mutual development. However, it can have the opposite effect if emotions are not acknowledged. The concept of a holding environment was proposed by Donald Winnicott. The phrase originates from the idea of a “good enough” mother-child relationship in which the mother, in accepting and understanding the child, translates into the child accepting themself (Winnicott, 1965, p 15). This concept might also be helpful in understanding how practitioners are able to contain parents' emotions.

As described in the methodology chapter, I have also applied Lacan’s psychoanalytic theory to identify the Imaginary (an ideal self) and the Symbolic (the social) orders in the language used by my participants. I have applied these metaphors as a framework to be able to express my interpretations of the narratives while privileging their narratives.

**4.2 John’s narrative**

*4.2.1 Going to nursery*

John started his narrative talking about his interactions with practitioners in chronological order, and he soon introduced the idea that going to school has been greatly beneficial for Maddie because school staff have taught her to communicate her needs and wants through sign language and using pictures, as she is non-verbal. He appreciates Maddie going to school because it has provided her with a means to communicate even though she does not talk at present.

1. like (1) before she went to school she (.) *couldn’t* (.) *speak*
2. she is non-verbal as it is now/ she doesn’t talk
3. but she’s come along/ she knows sign language

*4.2.2 Identification of needs*

Throughout his narrative John seems to posit that Maddie’s disability is defined by others. In terms of identification, the possibility of having a child with SEND has always been in John’s mind because it runs in his family and he has several diagnoses.

His mum also had shared that she thought there was “something there”:

40. When Maddie was born and developed after one year old/ my mum’s seen me in Maddie but twice as bad/ so my mum said to us she thinks there is something there.

He gives his mum some authority on identifying Maddie’s disability because she had “...seen it with him”. However, for John, Maddie seems to acquire her identity of disabled child when the health visitor tells him that Maddie has sensory needs.

198. John: yea, when she said cause she said she’s definitely got sensory needs

199. but she said she’s going to refer her to obviously get a dia (stuttering) (.)/ just to see if she’s got anything else

200. and then (.) then I phoned my mum after it and my mum said: “I told ya.”/ And I said: “You did”/

201. so we knew. We kind of knew then that there might’ve been something (.) there/. In the back of our heads, in the back of my head I knew from the day she was born

*4.2.3 Diagnosis*

John described the identification of sensory needs and autism diagnosis as a “relief” (line 47) because it is an explanation for others of why Maddie does not comply with society’s expectations of behaviour in social situations. I was surprised by his acknowledgement that the benefits of the diagnosis came from mediating relationships and perceptions of others rather than changing Maddie’s way of being. This is very different to being diagnosed with a physical illness and I wonder if the word diagnosis is signifying the same concept in both instances. Lacan’s proposition of self being dependent on the social seems to be illustrated in the following extract.

1. I know she is not/ (1) cause people look at her cause she has kick offs in like town and everything
2. (.) and people just stare.
3. Then (.) they don’t know to say something to you or not and then some people say to us (.) what’s up?/ I said “I don’t know”/ but *now I can say*.
4. Someone told me the other day: is there anything…?/ Does she have disabilities?
5. Now I can say yea/ she’s autistic and sensory needs so
6. (.) that’s kind of (1) it’s like a *label* but it’s not, *it’s more*.
7. There is a diagnosis of why she’s like she is/. She is not just a naughty child.
8. She is (.) there is something mentally wrong with her.

John refers here to the social convention of how children are expected to behave. I think that the power of this grand narrative provided by Western culture is evident in the above extract (Foucault, 1980). John seems to be trading off Maddie not being considered a naughty child, which is condemned by society, for having “...something mentally wrong with her”. Not at any point in John’s narrative did I perceive he contemplated the possibility of an alternative narrative in which the person is not defined by a disability in negative terms. However, looking at the narrative’s structure might indicate that despite vehemently asserting that disability is “bad” and “wrong”, he feels uncomfortable with the notion that Maddie, who has a disability, is “bad” or “wrong”. He seems to distance Maddie from being wrong by changing “she is” to “there is” in line 54. He also finds it difficult to articulate what the label brings:

63. cause (.) it’s (1) I mean (.) it’s not (.) you are never going to get rid of it/. It’s a mental disability.

I interpret that this could be because a “diagnosis” might signify more than relief for John, as it confirms that there is something wrong with Maddie.

John justifies the need for a label using his own experience of disability and being labelled with, “ADHD, autism, dyslexia, dyspraxia and Aspergers” (line 28) in the 1990s because at that time “...you were just a naughty child” (line 59). John changing the subject from “I” to “you” might be an attempt to depersonalise being considered naughty by others, perhaps because he feels emotional pain at being the target of this assumption. As I wondered how these diagnoses might have affected and affect him, he seemed to link them to mental health problems:

1. I’ve got diagnosed/ (.) I think (.) I was born with ADHD, I was diagnosed with autism at 4 and I’ve been on tablets since I was 5.
2. So I am on *sleeping tablets*, I am on day tablets
3. and *people say* how do I *deal with it* on a day to day basis.
4. Some days I have good days/ some days I have *really bad days* and I can’t go out of the *house* (.)/ I have to stay in the house but (1)

John seems to be holding a pathologising and deficit view of SEND prevalent in Western societies (Billington, 2000, 2006b), which might be helping him to navigate relationships with “...people outside the house” so he can be seen by them as coping with his way of being. However, this seems to carry an emotional burden, as he is not able to share his experiences with others. Relief to this emotional pain also comes from another person, John’s wife, who “deals with it”, perhaps meaning that, as she works with adults with autism and ADHD, she understands John so he does not need to hide from her.

1. but my wife, she is a carer/. She deals with it

Lacan’s work helped me to reflect on John’s understanding of disability and having a diagnosis. By looking at how signifiers are interconnected in the narrative I perceived that having a disability is more complex for John than simply having a label. In stanzas 27 to 30 he finds it difficult to explain why he thinks that having a “massive” spectrum of conditions nowadays is much better than being diagnosed with one condition like when he was a child. In order to explain this, he related Maddie’s experience at school. He values the school’s offer to refer Maddie so that she can have individual support to help her when she becomes dysregulated. He seems to imply that this support must be orientated towards meeting needs (rather than be in place because Maddie has a diagnosis). He also values that nowadays there is a broad range of training for parents and that paediatricians are “....looking at everything in the autism spectrum”, which would also help to identify the need to help Maddie regulate. This appears to be in line with current legislation in which support is provided according to need and not a diagnosis of a condition.

134. (.) It’s the same with the courses, there is a lot more to do with autism/ but it’s not just autism/ it’s for the whole thing

**Toni**: [for all special needs]

135. **John**: it does not just specify on the one disability (.)it’s the whole disabilities

136. and that’s what I like about them

137. ah (.) The paediatricians as well/. They don’t just (.) When you go, they do not just look at one thing, they look at other things (.) they say I’m not just looking at if she’s got autism/. They look at everything on the autism spectrum: the sensory needs, the autism, stuff like that

138. and that’s what I like about them now.

*4.2.4 Behaviour*

John found it difficult to put into words what happens some days when Maddie becomes dysregulated. It might be that John did not know why it happened so could not explain it. However, it could also be that Maddie’s distress in school and staff not being able to “handle it” hurts him to the extent that he finds it difficult to think and talk about. Maddie’s distress seems to be a big worry for John.

133. because some days she (.) we’ve been a couple of times we had to go to pick her up/ because she’s too much for them to handle with kick offs and anything like that/ so we’ve actually had gone a couple of times to pick her up (cough) to get her/ and, ahh, it’s like (.) some days (.) sometimes (.) it’s like (.) err (.) it’s like (3) I don’t know

She becomes dysregulated at home and John and his wife appear to take the brunt of it. I felt compassion for how difficult it must be for John and his wife to see their daughter in such distress. In this intimate situation at home I feel that ‘the social’ still seems to be present. John contradicts himself by stating that outbursts happen indoors “away from others” gaze whilst giving an example of when they happen outside and feeling the need to explain himself. This perceived requirement for an explanation might be a result of Maddie’s behaviour being considered unacceptable according to social conventions. I wonder if a different understanding of these behaviours by society would help John to reach out for support without judgement, and relieve his emotional distress.

170. (.) people don’t see what happens behind closed doors with Maddie/. The times she is out she is the happiest (.) kid

171. but sometimes she couldn’t be

172. and then they say why she doesn’t have a pram and stuff like that/ (little stammer) It's because if she comes off a pram and she does not want to get back she kicks off

173. but then when we get home/ she hits us, she slaps us, she

174. people don’t see what happens behind closed doors/. It’s always (.) they always see what happens out the doors.

**Toni**: yea

175. **John**: where she is always her happy, normal self

*4.2.5 Describing “normal”*

John seems to link “normal” with happiness and behaving in a rational way. He might be drawing on discourses reminiscent of normative assumptions in early child development. Billington (2000) questions this discourse by exploring the link between “normal” and psychopathology, which results in controlling, regulating and making groups deemed unreasonable, thereby, normal becomes a question of economic and political power (Billington, 2000). When I asked John later on about his hopes for Maddie in the future, he wished for her to have a normal life, which he “knows” is what everybody wants. This reiterates that he is describing “normal” from others’ point of view.

224 **John**: ah (3) I think it’s (.)/ I know everybody said this/ (.) Maddie have *a normal life*/. Not be ah (2) it’s (1)

However, when he reflects on what normality means, he describes “normal” in a highly personal way. “Normal” for John is related to his identity as a father. It is not being like his dad, who pushed him aside because he thought John was naughty. It is “being in the picture” for his daughter.

1. **John**: it is/. It is difficult to define normal because obviously my upbringing with *my mum*.
2. I, obviously, my father wasn’t in the picture
3. So (.) but I said to N when I was going to have my child, I wouldn’t be like *my dad*.

*4.2.6 John’s identity as a father*

John’s identity as a father appears to be a central narrative in his interview. He had tears in his eyes when he explained that he blames himself for Maddie’s way of being because he also has several diagnoses. However, when I remarked that he is doing a good job bringing Maddie up, he talked about others being “amazed” at how well he looks after Maddie, which turned into his own amazement.

1. They are *amazed* at how well I’m dealing with *Maddie/*, bringing her up *as well*.
2. Sometimes I’ve got to have her on my own and they didn’t think I would be able to look after her.
3. And I didn’t think *myself* I would be able to (.) eh, look after her myself/, but *oh*, I was amazed myself

|  |
| --- |
| Reflection  After my reaction to his expression of emotions, I think John felt safe and comfortable to talk about them, and he did. I think this is a good example of how his narrative was co-constructed during the interview. |

I interpret here that John refutes a within-child deficit view of disability, when he vehemently expresses that he does not care about disability. He uses a concrete example of “them” offering screening for Down Syndrome during his wife’s pregnancy, which he refused. His love for his children seems to be a bigger part of his identity than the narrative of deficit and impairment, and fatherhood seems to bring John fulfilment and satisfaction. I think that practitioners and others' understanding of this overarching narrative of love and productivity might be key to valuing disabled people in society.

238. So (??) I said to N when we do get pregnant, if it is a boy or a girl I’m not going to be like (.) whatever my daughter or son wants, they get.

239. I’m not going to put them aside disability or not/. They are still my daughter/ I look at them (.) I do not look at her as having a disability,

240. it’s just my kid.

**Toni**: yes

241. **John:** I don’t care

242. (.) because they said (.) eh, as well to do the test for Down Syndrome

243. but I said to N they’ve given you this paper but I don’t want it/, I don’t want it/. I don’t care if it comes Down Syndrome.

244. I’m gonna love it/. I don’t care what it’s got or what is wrong with her, I’m still going to love her/, love the baby/. I don’t care.

John’s emotional investment in fatherhood is apparent when he uses the subject ‘we’ in the phrase: “...when we do get pregnant” (line 238). I think that John changing the subject from “they” to “her” to talk not only about his daughter, but any children he might have in the future, indicates that this investment is one of his core values and is not entirely dependent on his relationship with his daughter.

I think John represents a father who falls outside what might be described as hegemonic masculinity due to aspects of his social and personal identity, for example, having been diagnosed with a disability as a child and not feeling accepted by his father. Connel (1995) coined the term hegemonic masculinity to describe the view that men are dominant in society. Subordinate groups include other male categories and women. Therefore, John’s narrative might be particularly relevant because current views of fatherhood seem to be based on the study of fathers who represent this hegemonic masculinity, whilst the study of fathers parenting their children in alternative ways, for example, fathers who are their children’s main carers, might have been neglected in research (Strier & Perez-Vaisvidovsky, 2021). With respect to research on fathering children with a disability, Boyd et al (2019) reviewed 21 studies on the subject and concluded that further research is needed to understand what influences fathers’ participation in family life. In his narrative, John defies hegemonic masculinity, if it is understood as holding a dominant position over other groups (Connel, 1995), when he talks about the intense bond he shares with his daughter and his nurturing role caring for her. In addition, the intense emotion of guilt he feels in relation to his daughter’s disability seems to contradict other previous research findings that a mother’s grief is more intense than father’s (Bruce and Schultz, 1996).

I found it moving listening to John’s description of his bond with Maddie and the satisfaction fatherhood brings him. Riessman (2008) cited Nietzsche’s idea of a prison house to express that all experience cannot be contained in language. John’s love for his daughter seems to spill over the words. I think poetic language would have been better suited to contain this meaning but perhaps the social narrative upholding that men should be tough suppressed the possibility of more emotive language.

1. **John**: she *cries* when I go out of the door and everything/. She’s my (.) from (?) she’s always wanted me, not N/. She’s my (.) she’s my baby girl.

*4.2.7 Understanding Maddie*

John considers that he and his family are well positioned to look after Maddie because they have dealt with disability all his life, which helps them to understand Maddie’s needs and wants.

1. so, ah, she (1) In Maddie’s head and my head (.) my mum says I know what Maddie is thinking because *I’ve got it*/.

This seems to imply the psychoanalytic concept of mentalisation. Hyman (2012) describes mentalisation as “...a sense of the actions of another person by recognizing that these actions are the result of reasons, motivations, feelings, thoughts, and desires in the mind of the other person” (Hyman, 2012, p 206). He proposes that mentalisation is a means to create a holding environment, meaning one in which a child feels secure and can learn. I feel that John is indicating confidence in that he can “hold” Maddie. John also seems to appreciate the ability of practitioners to enter Maddie’s world and follow her lead during a paediatrician’s appointment, although I felt that he also grappled with the need for her to abide by social conventions of good behaviour.

99. ah (.) and the stethoscope she wanted so he gave it to her

100. and he played with her/ He didn’t tell her to sit down.

101. She went around the room and did what she wanted.

102. If she wasn’t allowed or something, obviously, we told her ‘no’ cause obviously she was at the doctor’s desk and she wanted to draw but he gave her some stuff to play with and it was

103. (.) If she didn’t stay there and he needed to examine her/ he followed her around the room.

104. It was absolutely brilliant with her, absolutely brilliant.

*4.2.8 Feeling safe*

John seems to find his wife’s ability to access training on autism at work a source of help and support. He is keen on highlighting that his mum is also his and his wife’s support.

73. But N (.) N struggles sometimes because she doesn’t understand what Maddie wants where sometimes I do/ cause I was like that at one point

74. so it’s kind of, ahh, she’s helping me because she’s dealt with it/ and I’m helping her cause I’ve dealt with it all my life and my family has

75. so (.) my family is my support as well/ (.) my mum, my mum is mine and my wife’s support cause her, my wife’s side, they don’t have disabilities in their side of the family/.

76. Maddie is the first one/ the first grandchild who has got a disability

77. but obviously in my side we’ve dealt with it (.) with me for 28 years so,

78. my family is my support

His mum seems to be providing a holding environment for Maddie and also John and his wife. Hyman defines a holding environment as “one that fosters the natural maturation and development of the full potential of each child” (Hyman, 2012, p 205). It can be argued that it is not only children who need a holding environment. John’s mum is also providing practical support by attending appointments with practitioners with John and his wife. This is what John’s nana also used to do. John seems to imply that his mum provides containment for his and his wife’s emotions during meetings with doctors. This might be in part because she is able to find and understand information in these visits not easily accessible to all parents and carers, indicating there are power differentials during these visits which need to be addressed (Billington, 2000).

1. **John:** Every appointment to do with Maddie and her disabilities my mum is there.
2. so she asks (.) She has *more of an understanding/*. She asks more questions than we do. She is like (.)

*4.2.9 Evaluation of resources available in the current SEND system*

I was also interested in learning more about John’s views on what needs to improve in the service provided by practitioners. John quickly identified waiting times to see different practitioners as an area that needs to improve. He seemed to put responsibility for the waiting lists on the way appointments are managed. However, he asks for waiting times to be cut “a bit”, instead of disappearing. I think this might be a result of current legislation’s needs approach to SEND, which might contribute to support being seen as a charitable contribution instead of a right. Sayers (2018) makes a compelling argument to change the current system to a “rights based system” to build “the capacity of individuals to understand, claim and fulfil their rights” (Sayers, 2018, p 617). She conceptualises rights as respecting human dignity in line with the International Human Rights Declaration (United Nations, 1948) and notices that they are different from the legal entitlements specified in the Children and Families Act (2014).

183 not to like go straight away (.) just to cut the times down a bit/ because I know people who have been waiting two and a half years now/ just to get an appointment/.

There seems to be a similar narrative when John talks about the need for respite for him and his wife. He asks for “...just a couple of hours to themselves” (line 166). John falls short of asking for financial support. I think this might be related to the stigma attached to asking for financial support (Bolton et al, 2022). This might explain why, despite finances putting pressure on the family, he asks for clarity on what activities he can access for free but not for financial support to be increased.

188. **John**: eh (2), I’m not (3) (quietly) to be fair/ I think it’s like I said with the waiting times/. Now we are just waiting for a piece of paper to have Maddie’s diagnosis in a piece of paper

189. because some places/ (.) we are going to go away and stuff/ (.) but some places (.)/ because Maddie is classed as having a disability/ she can go free to some places/ so like takes pressure off us because of the money side of things.

**Toni**: yes, yes

190. **John**: but the thing is some places, they need proof, but we haven’t got the proof/

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1. and so sometimes Maddie has to miss out/. I’ve told my *wife* and Maddie to go and I’ve missed out/ cause sometimes we can’t *afford it* cause it’s… it’s

*4.2.10 Uncertainty*

At the end of the narrative, John talks about his plans to have another child depending on Maddie’s development. This might explain his attempts to work out the possibilities of having a child with a disability. His conclusion seemed to be that he would have to sit with uncertainty.

*4.2.11 Summary*

John’s story presents a combination of complex narratives. Some of them relate to the role of labels in preventing others’ misinterpretation of Maddie’s behaviours so she is not seen as “naughty” or “bad”. As a result, he welcomes labels and the within-child deficit needs-based discourse as a means of giving an explanation to others of Maddie’s behaviours, even though this means accepting that there is “something mentally wrong” with Maddy. Maddie’s disability is a source of distress for him, particularly when he sees Maddie herself in distress. I interpret that it might be also particularly poignant and upsetting to him thinking that she might be rejected by others as he was when he was a child. Blaming himself for Maddie’s disability seems to be another source of distress.

In addition, practical issues, such as caring responsibilities, finances and uncertainty about the future, also seem to worry John. However, he expresses that disability does not matter to him and that he is going to love his children regardless. This parental love and the bond he shares with Maddie seem to bring him satisfaction and a new identity he is proud of. I have interpreted that others are once more involved in creating this identity because they are amazed at how well he is “dealing” with looking after Maddie and then, John also amazes himself.

John seems to find that his wife and his mum provide containment for his emotions. His wife has experience working with adults with developmental disabilities and can access training and information, while his mum has the experience of bringing him up. Therefore, their input in interactions with practitioners seems to reassure John. Another source of reassurance is his ability to “know what Maddie is thinking” (line 72). John has a positive outlook on his ability to care for, and understand, Maddie. He expresses that it is also essential for other members of the family to be able to relate to Maddie, and by extension, the practitioners working with her.

**4.3 Kate’s narrative**

*4.3.1 Pushing all the time*

Once I introduced the research question, Kate started her narrative identifying the first practitioner she contacted, the SALT, and reflected that “...we did struggle a little bit with him being born in the middle of Covid” (line 6). It appears to me that this is Kate’s careful way of beginning to tell her story to a new person and indicates the performative function of the narrative. I feel that Kate is trying to be understood as reasonable and credible by diminishing the struggle as “a little bit” and reasoning that it could have happened due to the Covid lockdowns instead of putting blame on people or the systems in place. However, Kate soon introduces the idea that she had to “...push all the time” to be heard by practitioners. This voice of “pushing” for help can be constantly heard throughout the narrative despite that it seems to be at odds with Kate’s preferred sense of self and identity, which I felt was apparent in the discomfort she demonstrated at being seen by others as a pushy parent.

23 (.) So I've/ I just feel like I'm having to push all the time to try

24 (.) and it's not really in my nature to be that pushy, but I'm just thinking if I don't/ (.) nobody will and…

The love and parental responsibility Kate feels for Lee are also palpable in her narrative, and she does not manage to hide that her struggle to contact practitioners arouses strong emotions within her. I interpret that she is consciously giving up her sense of being reasonable and being perceived as such to get help for her child.

176 But from a selfish point of view Lee is my priority

177 **Toni**: No, it's not/ obviously/ and it's not selfish at all/ it’s a

178 **Kate**: and as I say, it's not really in my nature to be that pushy

179 But (.) because he is my everything./ I want the best for him/ ah (.) so, yeah/ I am onto them all the time.

180 I am pushing for that follow-up appointment/ because I just think it's important that we get that help

|  |
| --- |
| Reflection  Kate’s feelings of guilt also evokes strong feelings in me because as a mother I empathise with her desire to help Lee and I think that wanting the best for him should be a reason to feel proud. Others’ judgments of parents being “pushy” seem to be driving these feelings and I wanted to let Kate know that I did not judge her actions as selfish. |

*4.3.2 Current SEND system*

I think that the shame of being considered “a pushy parent” might be fuelled by the current legislation’s needs-led approach to SEN. According to Sayers (2018), this deficit- based SEND system views people with disabilities, who do not meet a criteria for “normal”, as “not one of us”(p 629). As a result, “they” need to ask for support. Perhaps implementing a Disability Rights Model in which support would be seen as a right, instead of a need (Sayers, 2018) could help parents like Kate, who feel they need to push against the system. Kate seems to reason that her position at having to push for help stems from the grand narrative defending that early identification of need is required to achieve good outcomes.

148 **Kate**: and everything you read. It kind of says that early intervention is so important/ for a good outcome/ that I'm thinking

149 this is why I'm really pushing

150 because I think he's only three/ (.) if there's anything I can be doing that will help him/ I want to be doing it

This cultural discourse reflected in the legislation has been criticised as prone to missing or overidentifying SEND when a developmental condition is not well-defined (Frederickson and Cline, 2015), and for the possibility of neglecting the implementation of provision in the child’s context to favour within-child strategies (Burman, 2017). I interpret that this narrative might also be encouraging false expectations in Kate as she waits for “something” to happen in her appointments with practitioners. Applying Lacan’s psychoanalytic theory, Kate might be seeking a desired whole image of herself and Lee in her interactions with practitioners (Lacan, 2006a). This means that Kate is searching for an image of herself created by others in their use of language. Lacan postulates that each of us is looking for this image of ourselves but it is an ideal image that we will never be able to reach (Lacan, 2006a). This points to an idealised self and might explain why Kate is not able to define “something” in tighter terms. I think it is of note that Kate uses the subject “you” in this narrative, perhaps to signify that this situation is not personal, it is what happens to anyone.

166 Even just having this appointment that we're going to next month has given us a big lift

167 because we think we've got something there

**Toni**: Yeah.

168 **Kate**: We’re going to this appointment and maybe something will happen there.

169 But sometimes you do feel a little bit in limbo

170 you've had your appointment and everything went great

171 ah (.) then/ like we had the appointment with speech and language/ and they said this is what we're going to do next

172 and then you don't hear anything for weeks and weeks and I'm thinking

*4.3.3 Feeling safe*

I perceived that Kate might be feeling immensely disappointed and frustrated about the uncertainty of when the follow-up of appointments will take place because she believes that Lee could be missing out on the support he needs. It appears that Kate needs practitioners to reduce this uncertainty for her emotions to be contained and so she can feel safe. I have interpreted that for Kate feeling supported by practitioners is a source of safety as she considers it to be priceless.

185. Because it is a worry/, isn’t it?/ You just want the best for your children and

186. (.) I think just having that appointment and knowing that there's somebody there/ that's fighting in your corner it's priceless/, really.

187. And (.) yeah, I just find that the wait between the appointments is the most frustrating thing.

The language of “fighting” has also been linked to the needs-approach narrative underpinning the current SEND system (Russell, 2013), in which the complexity of providing appropriate provision has been reduced to meeting certain criteria. However, I hear Kate’s desire for containment pitted throughout her narrative. For example, it seems that she has not reached out to find emotional support from practitioners because she feels she has a good family and support network (lines 130 to 133). However, she is quick to contradict me when I articulate that she has not needed emotional support.

134 **Toni**: Right. So you haven't needed it.

135 **Kate**: No, no/ I mean I do feel/ (.) A little bit/ (.) when they mentioned the autism and things.

136 And I did mention this morning/ when I went/ (.) that, I didn't know anything about it/. I don't know anybody who's autistic

137 and I think that/ at the minute we are a little bit in limbo because he hasn't had that diagnosis

I wondered if the meaning of this apparent contradiction might also stem from Kate’s need for containment to make sense of special needs and a diagnosis of autism, which is “alien” to her (line 153). Williams' (2013) application of Bion’s work to EP practice, which I think applies to other practitioners' practice also, helped me to make sense of Kate’s seeming interpretation that not having a relationship with the health visitor and other health practitioners was linked to the check-ups completed by them not being helpful. I think this also hints to Kate seeking containment in her interactions with practitioners.

46 **Kate**: We didn't know each other.

47 We didn't have that relationship which

48 (.) I think a lot of it was down to Covid

49 (.) we did have a couple of telephone calls/ (.) from different people/ (.) early on.

50 They kind of discharge us quite quickly when there was not

51 (1) He suffered with colic and things like that/ (.) there was no real/ (.) everything was fine with check-ups and everything so they didn't have (1)

Kate seems to find containment in the groups she attends for families with children with SEND. She describes these groups as a holding environment, meaning that they foster protection and security (Winnicott, 1965). Containment in the groups might be arising from sharing experiences with other parents and mutual understanding of each other’s experiences.

207 **Kate**: They've been really good/. Yes/, they've been really, really useful and

208 like I said/ just to see other parents in the same position

209 and hearing about things that have worked

210 and even (.) maybe older children/ my child wasn’t talking at three but now they have started/ that gives you a little bit of support that/, ah (.) Yeah, they were late

211 **Kate**: yeah, and also with little things/. Maybe not even connected to the speech

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213 and it's quite nice to be around children/ that similar in nature to Lee

*4.3.4 Knowledge and power*

I felt that Kate clearly articulates on different occasions during the narrative that she did not feel practitioners were taking her seriously; they were not listening to her. At the same time, she justifies their actions by articulating her lack of knowledge and power as a first-time mother:

69 Ah (.) maybe that's it/ (.) but as I said, Lee is my only child/ so I've got nothing to compare him to

70 but in my opinion (.) it wasn't.

71 And also/ my mum/ said to me/ it wasn't normal.

72 But yeah/ when I was saying that/ I didn't really feel like I was being taken particularly seriously

and also accepting the constructed ‘truth’ that parents worry unnecessarily.

77 and It’s also hard because/ (.) I mean/ (.) you hear it *all the time/* and you do get some people that maybe/ (2) push for things that/ that are not there/ and *I get it*”

78 And that's why/ I think it's so hard over the phone to kind of know/, whether somebody's maybe, maybe/ (.) just being a little bit/ ah (.) worrying unnecessarily/ or whether there is something

Power differentials between parents and practitioners have been identified by research (Douglas et al, 2022), so they do not seem to be related to Covid lockdowns. I think that Kate’s reference to Covid to explain practitioners not attending to her concerns might have been stake inoculation as suggested by discursive psychologists Potter & Wetherell (1987). This would be a discursive device Kate applied because she expected that her narrative would not be accepted by others or it might be undermined (Potter & Wetherell, 1987). I think she might have told her narrative many times before and Covid is part of it but I am also conscious that I am a practitioner and she might be anticipating a rejection of her narrative from me. In the field of educational psychology, this sort of narrative brings reminiscence of Sewell’s (2016) analysis of epistemological oppression in practitioners’ practice. Sewell proposes that unequal participation in knowledge construction impacts our understanding of the world and promotes oppression of those excluded from constructing knowledge (Sewell, 2016). In this case, Kate is adopting a construction of herself as a first-time mother who worries unnecessarily as she lacks knowledge. In this situation, Kate seems to look for allies who can “push on our behalf” to exert more power to help Lee. The staff at Lee’s nursery seem to fulfil that role.

124 and I do feel that /(.) by having them pushing on our behalf as well/ (.) it's not just me saying there, there's something

**Toni**: [It’s the school]

125 **Kate**: It’s not an independent person saying/ I think he does need that bit of extra help/ so I am grateful to them for that.

*4.3.5 Diagnosis of autism*

I found it difficult to understand why Kate seemed to think that if Lee is diagnosed with autism she will need to parent differently. She attempts to articulate reasons but they do not seem to be related to a diagnosis.

138 and maybe when he does get it/ if he gets it/ ah (.) then it'd be helpful for me to be able to know how to parent him differently

139 because it’s hard when you can't communicate.

140 It's hard when (.) you're not able to say don't do that/ or don't run on the road/. It’s hard because I’m having to

Kate seems to fully accept Lee’s way of being, so she is already able to parent him from a place of understanding and compassion. It seems to me that Kate’s anxieties spring from others’ constructions of Lee.

155 And he’s great/ and he's happy and to us he is perfect

So, why does she need to change her parenting if Lee is diagnosed with autism? Parenting differently might mean changing Kate’s positioning towards the grand narrative of needing to improve or fix a deficit in Lee. However, if this deficit does not stem from within Lee, who is perfect to his family, it must stem from the challenges he will have to overcome when he is older through social interactions within contexts he will encounter outside home.

156 our perfect little boy/ and I think/ (.) But I'm more kind of thinking as he gets older/ it's gonna become harder if he can't communicate/. It's more for his needs, really, I'm thinking

157 (.) if we can/ sort of build all other ways of communication for him when he's not home/ when he is in nursery and things like

I think Billington’s (2000) challenge for EPs to reflect on their core values to decide which view of autism they favour illustrates well the different parenting practices that might derive from the above epistemologies. Constructing autism as a within-child deficit-based condition could potentially involve advocating for strategies focussed on changing individual behaviours. In contrast, viewing autism as a relational condition might favour adapting the environment to help the child function within it. These are constructions of autism practitioners should become aware of so they can decide on their positioning and advice. Kate has no experience of a diagnosis of autism and it seems that as she interacts with practitioners she is learning about the support available to help Lee function best. I think this is an indication of the practitioners’ responsibilities to construct Lee’s autism (if he is diagnosed) together *with* Kate in order to overcome the constraints attached to grand narratives, thereby increasing her agency to parent him.

*4.3.6 Uncertainty*

I have also reflected on the voice of uncertainty expressed in Kate’s narrative as a worry arising from the new challenges and situations looming as Lee grows up. Once again, she seems to be reaching out to practitioners to help contain these feelings.

157 We've started potty training/ and I think/ at the minute he's okay because he's at home/ but if he goes to nursery/ how is he gonna tell them that he needs the toilet?

158 Just little things like that/, I'm worried about that.

159 if anybody can help me/ (.) in how to deal with these things/. I’d find it really useful.

*4.3.7 Summary*

The voices heard in Kate’s narrative are intertwined and filled with complexities. A strong narrative which can be heard refers to Kate having to “push all the time” so Lee can be seen by practitioners and interventions can be put in place early to help Lee communicate with others. Acquiring the identity of a pushy parent is uncomfortable for Kate but she seems determined to continue “pushing” to help Lee. This narrative of the importance of early identification embedded in current practice seems to be behind the need to “push”. Kate wants to learn about autism and how to best help Lee and seems prepared to parent him differently to help him communicate, despite Lee being “great”, “happy” and “perfect” to his family at home. I think this indicates that practitioners have a responsibility to construct the developmental disability with Kate to embody helpful strategies.

Kate gives different reasons for her perception that at times practitioners have not taken her seriously, for example, Covid lock downs and being a first time mother who “does not know” and might worry too much. However, she expresses the need for better communication with practitioners. Having a relationship with them seems to be the key to good communication and, thereby, containing anxieties related to uncertainty in the future and making sense of what a diagnosis might mean for Lee and the adults around him. Being supported by the rest of her family and being able to share these emotions with other parents also seems to provide Kate containment for them, enhancing her wellbeing.

**4.4 David’s narrative**

*4.4.1 Everything is fine*

David’s narrative starts by stating that everything has been very good. However, he seems to contradict this statement by adding that it has been difficult as Rob does not want to talk.

1. **David**: so far everything’s been very good with Rob
2. even though it’s been a bit difficult because (.) with him not wanting to talk/. You know, he knows words he just doesn’t want to talk.

I have interpreted that “everything” refers to interactions with practitioners, as it was about this that I had asked and David focuses on these interactions afterwards. However, he acknowledges a wider picture by adding that things have been difficult because Rob “...doesn’t want to talk”. David opening his narrative in this way made me feel a bit uncomfortable. I was reluctant to accept David’s proposition that Rob did not talk because he did not want to because this view seems to give Rob agency when it comes to his needs, so others can blame him for them. However, later on in the narrative the great efforts David makes to understand Rob’s needs and wants are evident. I think that by starting his narrative in this way David wanted to ensure that I was not going to perceive Rob as having something wrong with him. This is in line with findings in the literature looking at the experiences of fathers of children with learning disabilities. Pelchat et al (2003) reported that fathers want their children to be considered “normal” in contrast to mothers who want their children's individuality to be acknowledged yet that they are also seen as no different from other children. Perhaps this might explain the finding that fathers are less likely than mothers to ask for help from others (Pelchat et al, 2003). Green et al (2013) also reported that fathers are more worried about social acceptability than mothers.

David seemed to need the support of others to arrive at his conclusion. He was quick to say that Rob’s teachers, who had experience and knowledge of child development and can be seen as having authority and expertise in the matter, told him that apart from being behind with his speaking “everything else was fine”.

1. They picked up on it at his nursery, C./ The teachers there said he seems to be a bit behind with his speaking
2. but everything else was fine.

“Everything else being fine” seems to be contradicted later on in the narrative when David acknowledges that Rob’s teachers asked for one-to-one support in nursery to help him with his language skills, and also because Rob had no sense of danger and additional support was needed to keep him safe.

364. **Toni**: ok, so what that extra-support needs to be focused on for you is the speech and language?

365. **David**: yeah, language and understanding.

366. Also, with him having one on one we feel like he’ll be a bit more (1) looked after, if that makes sense.

366. Not that he’s not being looked after now/. It’s more so if there is someone there being one on one with him

367. cause he’s just come home a few times with bumps.

It was also needed to keep others safe.

379. **David**: yea, cause (.) I understand where they are coming from with it

380. cause I watch him at home.

381. I am the one stopping him breaking himself (1).

382. I am the one who gets broken stopping him breaking himself

*4.4.2 Overcoming disability*

At this point in the analysis I turned to Frosh’s (2008) proposition that “what is not said” in a narrative might be so because it is “too terrifying, disgusting or traumatic” (Frosh, 2008). In other words, David could not articulate that Rob has a disability or that something more general than language difficulties is not “fine” because he might have found it too terrifying to think about it. I wondered why this would be. It is possible that David was rejecting endowing his son with an identity of having something wrong with him because it would mean rearranging his expectations for Rob in the future. However, his expectations were already changing according to Rob’s way of being. I have interpreted that by rejecting that there was something wrong with Rob, David seemed to reject the within-child deficit grand narrative, which is arguably widely accepted in western society (Billington 2000, 2006a). As a result, he might have been trying to overcome the stigma attached to having a child with a disability in Western societies, which has been reported in the literature (Holland et al, 2018, Green et al, 2013). There are several accounts of parents rejecting the grand narrative of disability for their child. For example, Davies (2018) rejected mainstream schooling and psychiatric involvement for her son, as when attending school her son’s mental health deteriorated.

When he did consider interactions with practitioners, I felt that David sometimes found the information given overwhelming. I do not think it is clear whether the information seemed too much because of the amount of it, or because of its content, which might refer to a different understanding of Rob to the one David upholds.

86. So it wasn’t like (?) in your face so (.) Sometimes it’s all a bit much.

87. They want to give you all this information/ and want to talk about this (.)

88. and you are like: ‘can you give me five minutes, please’ (quiet laugh)

David appears to have strategies to protect himself from information he finds overwhelming. Sometimes, he “does not want to know” because he is the one looking after Rob, and he is tired.

332. and all the people we have been seeing have been really friendly and helpful mostly.

333. I can’t think of anything bad with any of them really.

334. **Toni**: You said mostly there? (quiet laugh)

335. **David**: mostly (1) sometimes I am just tired so then/ I just don’t want to know.

336. I am the one who stays up at night with him, you see.

I think David means that he is the one who looks after Rob “24/7” (line 372) so he knows him best. As a result, advice from practitioners needs to empathise with this to be accepted and helpful.

It seems that practitioners supporting Rob have put forward Rob’s needs to David as specific needs to be supported in different ways and they have not mentioned a more general developmental disability. David appears to lean on these expert accounts to reject a grand narrative of within-child deficit. Drawing upon Lacan’s ideas, it might be posited that David needs others, the social, to construct Rob’s identity, and his own identity as a father, in the subconscious. The social is therefore interrelated with our identities and sense of self. In this case, the social are practitioners. This is illustrated in Rob’s visit to the paediatricians. They diagnosed Rob with hypermobility but said that there was nothing wrong with Rob apart from that. David paused twice when saying “…there was nothing wrong with him apart from that.” I think this might be because he was thinking about Rob not being able to talk yet, as it could be something else “wrong”, it worried David and his next sentence refers to it:

154. and he says/, well, it seems like he’s got hypermobility

155. and apart from that/, his hand- eye coordination is fine.

156. He’s inquisitive

157. there’s not (1) anything wrong with him apart from that (1).

158. He said his speech will probably develop over time himself.

*4.4.3 Maintaining positive interactions with practitioners*

David describes the way he is talking with Rob’s teachers about Rob as having found “common ground” (line 410).

409. David: yea, with his teacher/. With his nursery teachers/, we’ve been able to talk to them (.)

410. we found common ground to talk about Rob

411. and even stuff that is not Rob. They ask how the house is coming along and stuff like that so (.)

I think this “common ground” consists of David appreciating practitioners identifying and providing advice and information to support Rob’s identified needs, which were the focus of his concerns, while not using a within-child deficit narrative, instead embracing the idea that “there is nothing wrong with him.” Finding common ground means that David evaluated his interactions with practitioners positively throughout his narrative. As I reflect on this, I hope that David and the practitioners supporting Rob can continue working collaboratively. However, I also wonder if the grand narrative of within-child deficit can be overcome once Rob enters a more structured educational environment with specific expectations. This is because, if he is not able to meet those expectations, the adults around him might blame a disability or others (the child, his parents, his teachers) for him failing these expectations.

On different occasions David states, “it is one of those things” (when he refers to the diagnosis of hypermobility in line 167, Rob not being interested in using language or signs to communicate in line 296, and Rob “getting there” when he pronounces letters in line 304). David does not seem to blame anybody for Rob’s needs, although I wondered if he might blame himself because Rob would not speak with him. I feel I want to protect this lack of blame because I believe it works in Rob’s best interest and also the best interest of all involved in supporting him. In my experience, blame seems to lead to conflict. This has been illustrated by Pellegrini (2010), who reflects on how the psychodynamic concept of projection, defined as “an outward deflection of anxious feelings and unacceptable parts of the self” (Pellegrini, 2010), influences social interactions in school. He concludes that educational psychologists can have more honest conversations with other practitioners and parents to problem-solve situations by identifying when projection might be happening.

David summarises different reasons for having positive interactions with practitioners. He appreciates that everybody has been good with Rob, friendly to him and his wife Lynn, and they have not overwhelmed them with information.

403. **David**: in general, roughly all of it/. They’ve been very good with Rob/ and very helpful and friendly with us

404. **Toni**: that’s really nice to hear

405. **David**: they’ve conveyed information over well if that makes sense

The practitioners’ friendly approach and that they conveyed helpful information, seems to provide containment to David’s emotions. In other words, they alleviate anxieties by responding in an accepting and friendly way (Hyman, 2012). I think that Donald Winnicott’s concept of a holding environment is helpful to understanding how practitioners are able to contain David’s emotions (Winnicott, 1965). In David’s case, being accepted and understood by practitioners who are attuned to him, helps him to accept his own emotions. As a result, David is able to reflect and think to create new meaning from his experience.

There are many examples in David’s narrative indicating this holding environment is what he finds helpful from practitioners. These include the playgroups promoting a sense of belonging because “everyone is there for the same reason” (line 81) and also because there is a balance between interacting with other parents, receiving information, having freedom to play with their child (lines 84 to 86), and the paediatricians being friendly (line 169). In addition, there are occasions David enjoys these interactions, for example getting along with Rob’s teachers.

412. **David**: Which is always nice cause/ (.) you like to get along with people who are going to be looking after your kids, don’t ya?

**Toni**: ye

413. **David**: you want to know that they are friendly and happy people

414. and they’re not (David makes a sound) ‘iiiiiii’

Other examples are Rob having fun during a hearing test (line 15), attending the playgroups (line 69) and everybody in nursery being nice to Rob (line 212). I think David means that feeling valued and Rob finding joy in the interactions with practitioners makes a positive difference for Rob and his family. It therefore appears that this feeling of containment comes through the interactions both David and Rob have with practitioners. This is not experienced as an intervention as David does not openly seek emotional support from practitioners. It is, instead, provided by practitioners accepting Rob and his parents and providing information without overwhelming David.

*4.4.4 When interactions go wrong*

David also gives an example in which the health visitor was not able to provide containment. He describes a visit by the health visitor as a negative experience because of her “condescending tone” (line 177). David seems to perceive that he was not being listened to, the information given was irrelevant to him and Lynn, and they were left without knowing if there were going to be follow-up visits. I noticed that David uses the pronoun “they” to refer to the health visitor, perhaps indicating that he is not unhappy with a person but with health visitors as a system (line 179). When David summarised why this interaction was “bad” he talked about the health visitor not being “bothered” or feeling emotions. It would seem that he was looking for an emotional connection with practitioners which he did not find in his interaction with the health visitor.

356. (.) apart from the health visitor coming around the house.

357. That’s the only bad experience we’ve had with people interacting with him

358. and that was just because/ (.) I don’t think she was really bothered

359. don’t feel emotions kind of thing

David described another negative interaction, which once more related to not being listened to, when he asked nursery staff not to let Rob play with water as it was winter (line 99) and because it was making Rob become ill frequently. However, nursery staff did not stop Rob from playing with the water and phoned David to say that Rob’s attendance at nursery was not good enough, which indicated to me that nursery staff in this instance were treating Rob and his family as a statistic related to the attendance rate, without understanding who they were as people, and what was happening for them.

117. **David**: they phoned me up to say he’s not feeling well, yea

118. and it’s like he has to have 48 hours off/. Well, there is the time, the attendance’s gone.

**Toni:** yea

119. **David**: and then they are complaining to us.

*4.4.5 Evaluation of resources available in the current SEND system*

David also talked about practicalities in his interactions with practitioners which have been helpful, such as not having to wait for the appointments with the paediatricians (line 329). Issues which David identified could be improved include that, “...there is not much to do with Rob” in the local area (lines 418). The problem seems to be that sometimes groups happen at the same time (lines 224-226) or David cannot find information about them on time to attend (line 426). It seems that not using social media (line 436) and the summer holidays compounds this issue (line 442) as they tarnish connection with services available.

David only can think of one thing he needs help with: looking after Rob for a couple of hours to give him and his wife a break from the intensity of looking after their child.

241. David: so, yeah (1) The only thing I can think of to help wise would be looking after Rob for a couple of hours.

David thinks that increasing Rob’s hours in nursery would be beneficial to give him and Lynn respite, and also to promote Rob’s language and communication skills (lines 313-314). However, this is not currently happening because increasing the hours implies financial costs.

255. We paid for about two months’ worth of Wednesday he didn’t go to/ so it was like (.) oh, why are we wasting our money?/ It’s £15 a week.

Following the SALT’s advice, David seemed keen to give Rob as many opportunities as possible to talk and interact with others, and wondered if Rob having more time with other kids when he was younger would have “helped him a little bit” but this was not possible because of the Covid lockdowns (line 217-218).

*4.4.6 David’s identity as a father*

309. **David**: I’m always busy/ I never stop/. I don’t get a break./ No matter what I’m doing/ I never get a break

The idea that looking after Rob is exhausting and that David is tired is presented on different occasions throughout the narrative. I think this is part of a narrative David adopts which I feel is perhaps more commonly used to talk about mothers and what motherhood is like. Constantinou et al’s (2021) literature review on maternal guilt indicates that mothers feel responsibility to enhance their children’s wellbeing while attending to a multitude of demands. I think David turned the tables on this narrative and presented himself as taking responsibility for organising childcare, as his children's main carer.

449. so I can drop Sam off at work/ and she can walk back with him/ and I can bring Rob

450. **Toni**: So you are organised, it’s the logistics of sorting everything out, isn’t it?

451. **David**: It's always my job that. Lynn, she would just have a nap.

**Toni**: right

452. **David**: She would sleep anywhere, her. She fell asleep stood up, waiting in line.

**Toni**: right

453. **David**: I’ve seen it.

I feel that the above extract is also an example of David introducing a comical note to his wife’s contribution to their children’s care. I perceive he might be deliberately contradicting a common narrative on the way fathers may be seen featuring in some mass media. Kelly (2015) refers to television series examples and research papers to propose that when women entered the job market in the 70s, the portrayal of fathers on television changed from authoritarian, problem-solving figures. However, David valued being able to discuss his views and experiences with Lynn openly, and them sharing similar views. He also described Lynn receiving support to breastfeed, I think to exemplify a caring activity she solely needed help with because it was an act related to her body (lines 457-479). I feel that David and Lynn’s shared understanding of their children’s needs may protect David from possible negative outcomes reported in the literature when mothers provide care for their children without enough support to meet the idealistic expectations upheld in western societies (Sear, 2021). Rob seems to embrace his nurturing role bringing up his children. He has moved from Brooks & Hodkingson (2021) description of the “Amazon Alexa father”, postulated to be the most common role for fathers in households nowadays, occasionally stepping in for the mother, to take primary responsibility for childcare.

In addition to taking the main responsibility for organising his children’s care, David is also building their house. I am aware that the family has moved to a new property and David is completing the building and repairs in it, which I think resonates with a masculine version of the woman’s responsibility to keep the house clean and tidy. He also shows emotional responsibility in his efforts to attune with Rob’s wishes and needs, for example, when he understands what Rob wants to say without using words (line 292) and when he accepts what Rob wants even if it is tiring (line 342). Nevertheless, David seems to put a humorous twist into his expressions of emotion and love towards his children, perhaps as an indication of the performative function of the narrative as I am a woman listening to him and he might not want to sound unmanly. This might be another example of stake inoculation in which David is using humour to prevent his narrative from being undermined by the listener, in this case, me (Potter & Wetherell, 1987).

481. He was tiny- tiny/. He was four weeks early.

**Toni**: four weeks?

**David**: yea, about that big (gesture).

482. He used to sleep on my chest with his feet dangling

**Toni**: ohh

483. **David**: yes, we used to lie in bed with him on my chest watching the laptop

484. Just watching him there like that (.)/ and he was snoring.

485. Rob snores/ like a train

**Toni**: (quiet laugh)

486. **David**: He gets that from his mum. Yeah.

David, arguably articulates a narrative at odds with hegemonic masculinity. In the same way as John, he develops a nurturing role connecting with Rob, attending caring duties “24/7”, organising activities for his children and also looking after their house. I perceive that David embraces narratives often used by mothers that might relate to intensive mothering, for example when he talks about being tired because he never stops and he looks after Rob “24/7” at different points in his narrative (Liss et al, 2013). In addition, he does not like asking for help unless he has to (line 237). Nevertheless, the fact that he finds support in Lynn might protect him against negative outcomes associated with the intensity of his experience (Sear, 2021).

*4.4.7 Summary*

I found it surprising that David did not refer to disability in his narrative. I think this was his way of overcoming a within-child deficit narrative which may carry stigma (Holland et al, 2018). However, he was prepared to make the issue of Rob not talking about Rob not wanting to talk, thereby, replacing disability with behaviour, perhaps because he might consider it less stigmatising. Despite ignoring disability in his narrative, David is keen to find “common ground” with practitioners to find ways to ameliorate Rob’s needs.

David seems to have identified that practitioners and others being friendly and nice to Rob will make a positive difference to his life, and this is what he seems to be asking from his interactions with others. This resonates with my experience of mothering two children. I want them to be happy and, in the same way as David, I hope they can be understood and experience positive interactions with others to promote their wellbeing. David is also able to identify unhelpful interactions with practitioners. These interactions are characterised by David feeling patronised or unheard.

In this interview David was able to describe the difficulties of being the primary carer of a child with special educational needs. However, he went beyond describing the difficulties related to caring for Rob. A prominent narrative was his dedication to looking after Rob. His commitment to finding ways forward to understand and communicate with him is saturated throughout the interview and brings the profound bond they share to the fore. I think David displayed a sense of pride at being his children’s main carer and he does not seem to contemplate changing Rob or changing this role (line 217, line 455). I think this indicates the complexities in David’s narrative. David is able to articulate the difficulties brought about by exhausting caring responsibilities but he does not seem prepared to accept the stigma which might be brought by his child being identified with a disability. However, fathering Rob is central to his identity and he embraces it with love.

**Chapter 5. Discussion**

**5.1 Introduction to discussion**

In this chapter I aim to continue my exploration of John, Kate and David’s narratives in order to address my research questions in relation to current literature. The chapter also highlights how the narratives of the parents taking part in this research suggest that broadening the paradigms and epistemological positions applied by practitioners, including EPs, can help educational psychology practice become an emancipatory force for parents and their children in their interactions with practitioners whilst providing resistance to oppressive practices.

My research questions are:

* What meaning do parents of children with SEND in the EYs give to their interactions with practitioners working in the current SEND system?
* What do parents of children with SEND in the EY say happens within these interactions to enhance their wellbeing and support their children?
* What is the role of the EP in supporting parents of children with SEND in the EY and in supporting practitioners to learn from parents’ accounts of their mutual interactions?

In the methodology section I have explored the subjective nature of social constructionist epistemology and the subjectivity inherent in telling and interpreting narratives. Therefore, I am not trying to generalise any conclusions reached as a result of this research as they are possible interpretations and there will always be alternative ones. The aim of this discussion is to reflect on the psychosocial and constructed nature of theory and practice and to question these processes while respecting the parent’s narratives as they are told in order to prevent myself taking an expert position and attempting to tell a “better story” (Frosh, 2008, p 36).

**5.2 What meaning do parents of children with SEND in the EYs give to their interactions with practitioners working in the current SEND system?**

*5.2.1 Biological underpinnings of disability*

It feels to me that a within-child deficit medical narrative based on a traditional model of child development which assumes normal child development and deviations from it has a strong presence in John, Kate and David’s narratives (Watson, 2018). There are instances in Kate and David’s narratives in which I have perceived that they view practitioners as experts who they hope can put in place interventions to ‘fix’ a within child problem in a similar way an illness can be treated.

168. **Kate**: We’re going to this appointment and maybe something will happen there.

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270. We want to try to see if we can get him to talk

**Toni**: yes

271. **David**: and whichever person helps to do that the most he’s going to be very happy

This idea might have been encouraged by the emphasis in the SEND CoP (DfE/DoH, 2015) on identifying need and putting in place provision early, therefore, encouraging parents to look at practitioners to provide expert advice. However, the SEND CoP (DfE/DoH, 2015) acknowledges that the benefits of early provision for children with SEND are not related to ‘treating’ a biological problem. There is clarification that these benefits lie in preventing a “loss of self-esteem, frustration in learning and behavioural difficulties” (p 86). In other words, the benefits of putting in place provision early relate to others’ understanding of the child’s needs and strengths, enabling positive interactions and learning experiences thus preventing harm. In my view, this raises the key question of how we can provide an education which supports every child without affecting them in negative ways. It would be helpful for practitioners to clarify where the advantages of early intervention lie and encourage parents to reflect on how their relationships with their children might have beneficial effects, such as promoting communication skills and enhancing the children and parents’ wellbeing.

*5.2.2 Navigating stigma through labels*

John, Kate and David's experience of their interactions with practitioners seems to be shaped in different ways, which I think accounts for the individuality of each of the participants’ previous experiences. However, I have interpreted that stigma acts as a canopy casting a shade over their narratives of their children’s needs and their interactions with practitioners, and others. Research has found that parents of children with disabilities experience different types of stigma, blame and guilt (Gray, 1993, Francis, 2012, Turnock et al, 2022, Timimi et al, 2016). I think the experience of stigma is firmly anchored in all three narratives despite not being named in any of them, which indicates that there is a complex picture emerging from these parents’ accounts. In all three narratives there seems to be anxiety about uncertainty in the future and the possibility of their children being rejected or misunderstood by others outside the home, including practitioners. On the other hand, they value practitioners and others understanding their children and being nice, friendly and following their children’s lead.

John, Kate and David’s narratives seem to support Timimi et al’s (2016) proposition that social, political, cultural and economic factors determine disability. It appears that these factors are also closely related to the way these parents perceive and experience stigma and their wellbeing (Čoliċ et al, 2022). The presence of stigma can be noticed in John’s narrative when he welcomes his daughter’s autism diagnosis as a “relief” because this label provides an explanation for others of why Maddie does not comply with society’s expectations of the way a child her age should behave. Labels seem to be the road paved by practitioners to enable the movement of blame and stigma of Maddie being “naughty” or “bad” to a biological deficit in her brain (which seems less stigmatising). Mallett & Runswick-Cole (2016) propose that a diagnosis of developmental conditions offers a “new normal” (p 70). Thereby, the condition becomes a “commodity” so parents can refer to its description as the “normal” way a child with a diagnosis behaves (Mallett & Runswick-Cole, 2016, p 70). This lifts blame from parents and provides an explanation of the child’s behaviour to others. However, children for whom this applies might be then seen in deficit terms used to define them “instead of everything else they are or could be” despite these conditions being culturally constructed without a biological basis for their diagnosis (Mallett & Runswick-Cole, 2016, p 72).

Kate is also seeking early diagnosis and early intervention for Lee as a means of supporting communication with others when he is at school and in the community. At home, Kate describes Lee as great, happy and perfect but she seems to be trying to prevent him becoming socially isolated when he is outside the family home, which appears to be a result of her perception of the stigma he would otherwise experience (Liamputtong & Rice, 2021). In David’s narrative, I have interpreted that stigma attached to disability presents in a diametrically opposed way to John’s and Kate’s. David ignores disability in his narrative and he reiterates that apart from Rob’s specific needs “everything else is fine”. I think this is the way he has found to overcome the stigma attached to having a child with a disability in Western society. He seems to value finding a “common ground to talk about Rob” (line 410) with practitioners who look after him. Common ground seems to consist of building a friendly relationship, in which I interpret that practitioners are attuned to David’s views on Rob’s needs.

Attending Foucault's analysis of power (Foucault, 1980), the narratives around diagnosis and early intervention might be viewed as unitary knowledges upheld by practitioners, and society in general. By definition, unitary knowledges are upheld by the majority in society as truths. However, if not questioned, they might silence alternative narratives. In the context of this research, they can be perceived as an influence over parents’ expectations from practitioners. In my view, bringing those alternative discourses to the fore might help eradicate stigma and blame instead of moving it around. Some examples of why these unitary knowledges might not correspond with an objective truth include controversies around the effectiveness of early interventions for children with autism. Russell (2016) describes this caveat in early diagnoses of autism despite DSM -5 advice (APA, 2013), and the great variability of behaviour in young children which encumbers an accurate diagnosis. In addition, a relational approach to LI, for example through play, also seems to be discounted in the guidance provided by the SEND CoP (DfE/DoH, 2015) despite the consequences of LI being relational, “...it is experienced within social relationships and situations” (Hambly, 2017, p 410) and affects children differently in different situations.

In a more general sense, Billington (2017) cites affective neuroscience to make the compelling argument that emotion is necessary to promote learning so linear cognitive models of thinking and learning dominant in educational policy in the 20th century might be inadequate. In the literature review, I explored research advocating a different ontological position to the traditional grand metanarrative of child development focussed on age related competences and deficits that ignore the child’s experiences and context. David, Kate and John’s narratives suggest that understanding development within a socio-economic context, for example in acquiring particular cultural skills, and intersubjectivity as the foundation for children's ability to communicate with others and engage in cultural life, might be helpful in eradicating stigma around disability for parents and so change their expectations of practitioners.

*5.2.3 Managing complex feelings of self-blame, loss, and happiness: parental love*

The narrative of loss and grief can be heard in the narratives shared. I felt John’s intense pain when he blamed himself for Maddie’s disability. David’s feelings of frustration and disempowerment at not being able to communicate with Rob are also palpable, as is Kate’s anxiety about Lee’s future as she fears that he might not be able to communicate with others outside the family home. Self-blame also appears in Kate’s account when she seeks a diagnosis and practitioners advise her to parent Lee differently so she can help him communicate (lines 137-139).

Čoliċ et al (2022) propose that parents blaming their parenting skills for their child’s needs might increase stigma internalisation, meaning the internalisation of negative attitudes upheld in society against a group (in this case parents of young children with special educational needs and disabilities). Perhaps this will be a temporary situation for Kate because she expresses self-doubt about her ability to parent a child with special needs as a relatively new mother and research has found that self-stigma presenting when parents have not yet developed a sense of competence in their parenthood skills decreases as they find evidence that they are acting in their children’s best interest (Eaton et al, 2016). In my literature review, I include research which has found that as parents become more experienced and learn about their child’s disability there is a shift from grief arising from child-centred factors to concentrating on societal factors (Bruce and Schultz, 1996, Brown, 2013). The narratives shared in this research support these findings. David and John both ask for respite to help with the daily care needs of their children, so they are able to rest and relax. Finances are also present in their narratives as a stressor.

In contrast to narratives of grief and loss, John, Kate and David also seem to feel great satisfaction parenting their children. I feel that this myriad of powerful emotions embodies the complexity of their experiences. John talks about his amazement at how he is able to look after Maddie, the deep connection they share (lines 245-252) and the joy and satisfaction it brings to him that she “...always wants me” (line 249). He displays an unequivocal sense of pride and contentment brought about by parenting Maddie. Kate also expresses the joy of parenting Lee overtly:

152 And he’s great/ and he's happy and to us he is *perfect*

David is keen to highlight his dedication to looking after Rob “24/7” (lines 372, 373) and feeling exhausted, but when I asked if he needs help he does not seem to wish to change the time he spends with Rob.

455 **David**: well, I stay at home and I look after Rob mostly so/ I’m fine with him (.) mostly

For these parents their children are precious; both feelings of loss and joy seem to be rooted in deep parental love. This supports an approach to SEND which accounts for parents' expectations and complex experiences and acknowledges the need to work cooperatively, as is reflected in the SEND CoP (DfE/DoH, 2015) guidance. However, current policy also supports a needs-based and child deficit approach to decide on which statutory provision is required to support children with SEND. This seems to be problematic because the ethos of a needs-based and individual deficit approach appears to be one of segregation, while the ethos of collaboration and understanding parents’ experiences advocates inclusion. A possible way forward to solve this situation might consist of considering ecological factors when assessing children’s needs, as identified while working collaboratively with parents.

*5.2.4 How can I be a good parent and do this?*

A powerful narrative in David’s account seems to privilege ‘doing things’ while he strives to be a good parent. This involves him taking responsibility for organising his children’s care and appointments and being always busy looking after them. I think this view of parenting might be influenced by current views of ‘good parenting’ in Western society, which involves “intensive mothering ideology” and holds mothers as in the main responsible for the development, health, and well-being of their children (Arendell, 2000, p 1194). It is of note that research has found that ‘intensive mothering’ might come with shortcomings as it might reflect “unrealistically high societal expectations of motherhood” (Constantinou et al, 2021, p 853), and has been related to maternal guilt (Constantinou et al, 2021, Sear, 2021). More research might be needed to clarify whether this is also the case when fathers are the main carers for children with SEND.

It is possible that a focus on ‘doing things’ is hindering these parents' ability to reflect on their parenting skills and their relationship with their children as being good parenting independently of ‘doing’ something. This might be the case when Kate is “pushing” to gain expert advice to learn how to “parent differently” (line 137). As a result, Kate seems to have reluctantly internalised an identity of “pushy parent” as she is always pushing to see practitioners who can advise her on how to promote Lee’s communication needs. I think that this position might also be influenced by a grand narrative of disability upheld in current SEND policy encouraging early intervention by practitioners who might be seen as experts.

John seeking a diagnosis for his daughter in order to prevent others from seeing her as ‘bad’ or ‘naughty’ also might be influenced by these grand narratives. However, he considers these diagnoses as lifelong conditions, perhaps because for most of his life he has lived with diagnoses of several developmental conditions and his focus is on others understanding Maddie’s needs (line 63). On the other hand, I have interpreted that Kate and David might be seeking early intervention as a ‘magic cure’ and, once in place, their children’s difficulties communicating with others will disappear, while adaptations to their context might not be considered early intervention.

84. And we've tried to put all these things in place and

85. I just think/ (.)/ we talk with him all the time/ we do all things that they said to do/ and

86. (.) as I said/ he is our only one so he gets our full attention/ there's/ he's the only baby in the house.

87. So Yeah, I do feel like we're talking to him all the time

88. and (.) there was no eye contact./ He wasn't responding to his name and

89. (.) I just didn't really feel like I was being taken seriously initially

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60. **Toni:** so, the speech and therapist, was it helpful advice?

61. **David:** I already knew most of it.

62. There was a couple of things

63. (.) we’ll try that but most of it we already knew.

Therefore, practitioners have a responsibility to clearly explain what early interventions are needed and why so that parents can feel heard, their emotions contained and their expectations adjusted.

*5.2.5 Summary and conclusions*

In this section I have explored the meaning parents of children in the EY with SEND I interviewed give to their interactions with practitioners. Whilst acknowledging the unique experiences of each of the parents, I also noticed what I felt might be shared narratives that provide helpful learning for practitioners.

I propose that there is a need to clarify the messages practitioners are communicating to parents on the biological basis of developmental conditions, which might influence their expectations of interventions and practitioners themselves. I have also discussed uncertainty for the parents about how their children will be able to communicate with others and anxiety around stigma that seems to be a major driver for the parents in this research to seek support from practitioners, for example, to obtain a diagnosis. Labels seem to move stigma and parental self-blame for the child being naughty or bad to a biological reason for their behaviour. Better social inclusion might eradicate this tendency (Liamputtong & Rice, 2021). Inclusion could be engendered by a change in traditional views of child development towards a greater acknowledgement of the influence of social factors on the child’s experience.

I have explored, too, the intense emotions parents expressed in their narratives, including the complex mix of grief and the joy their child brings and I propose that practitioners need to understand this and their important role in being able to contain these emotions.

Finally, I have suggested ways in which current approaches to disability and parenthood in Western societies might be influencing the parents’ narratives, including the gendered nature of interactions. This indicates that social factors, such as gender, need to be considered by researchers and practitioners so this influence can be reported in research and parents can be better understood by practitioners in practice.

**5.3 What do parents of children with SEND in the EY say happens within these interactions to enhance their wellbeing and support their children?**

*5.3.1 The relevance of relationships*

David, Kate and John highly value having relationships of trust with the practitioners involved in their children’s lives. They all have support networks in their families so they are not looking for specific emotional support from practitioners. However, having a positive relationship with practitioners seems to have a therapeutic effect, improving their emotional wellbeing. Occasions in which this relationship has not worked, for example, when David found the health visitor’s attitude was condescending, or Kate did not have a relationship, also with a health visitor, seemed to have the opposite effect, introducing resentment.

Kate explains that there had been missed appointments with the health visitor due to the Covid pandemic. However, I interpret that the difficulties resuming this relationship seemed to derive from a breakdown in communication, in which the health visitor is performing her role focusing on tasks and checks instead of listening and understanding. In the previous chapter I hypothesised that the importance of relationships between parents and practitioners might be explained by Bion’s concept of containment, so that parents feel safe in these relationships (Bion, 2018). Thereby, overwhelming feelings for parents such as uncertainty about the future, or frustration related to difficulties communicating with their children, can be understood and regulated. I also have discussed that a holding environment as described by Winnicott (1965), in which parents feel emotionally safe, can also be provided by creating peer support groups offering the opportunity for parents to meet other parents with children who are similar to their own and share their experiences.

In their narratives, the parents value different aspects of their relationships with practitioners which seem to create favourable conditions for containment to occur, for example continuity of care so the relationship can develop. The practitioners' friendly approach to them and their children, and practitioners providing information and communicating what the next steps are in a timely manner to reduce uncertainty, also seem to be helpful. Kate explicitly asks for someone being in touch to show interest in how things are going (line 204). I think that these are favourable conditions in helping parents process their emotions and thoughts, and contain them, mediated by intersubjectivity between the individuals involved in these interactions, enabling the creation of new meanings. The concept of intersubjectivity has been embraced by psychoanalytic theory and studied by philosophers in the 20th century. Zahavi’s (2001) review of theories of intersubjectivity discusses Heidegger’s perspective that intersubjectivity unfolds from “what was already there” before an encounter takes place, meaning the influence of the world, the context in which people’s subjectivity takes place. This is relevant to this research because it highlights that parents and practitioners will be influenced by legislation, the media and personal experiences (the social). Zahavi (2001) also considers Sartre’s position that intersubjectivity occurs when we become aware of the way we appear to the others and that this might not just create understanding, but also conflict (p 157).

Lacan’s work also puts our understanding of how we appear to others in a central position when thinking about why parents might consider that having a positive relationship with practitioners would be beneficial to them and their children. He applies the concept of the mirror stage. This process would start with parents feeling distress because the way they behave or see themselves is not in tune with the image they have of how they ought to be. For example, parents might feel frustration as a result of the difficulties they experience communicating with their children or helping them to self-regulate because they consider that ‘good parents’ can communicate with their children. According to Lacan, practitioners are part of the Other, the social, represented in the Symbolic Order (Lacan, 2006a). Therefore, the practitioners’ response to parents’ distress will shape the parents' sense of self. In this way, intersubjective experiences between practitioners and parents are able to promote a positive sense of self in parents when they derive a shared understanding.

*5.3.2 Facilitating productive communication between parents and practitioners*

John finds that practitioners are better at listening to parents than when he was a child, and appreciates this. However, Kate told me that she has not been “taken seriously” by practitioners (line 71-72). David also provides instances when he has not been listened to, and this feels frustrating for both of them. In Kate's narrative, not being listened to seems to lead to insecurity and in David’s narrative to a shut down from the information given by practitioners, perhaps meaning that he needs to be listened to (as well as his wife) as he is the one looking after Rob “24/7” (line 372). From a social-constructionist position, Gergen (2022) describes transformative dialogue as a means to facilitate generative interactions between people. He proposes that the context of the interactions influence them, which perhaps could be understood as Heidegger’s “being there”; that which is already there before the interaction takes place.

In addition, listening to parents narrating their experiences might promote understanding by practitioners of their emotions and thoughts, and support them to be transparent about their own vulnerability. By communicating their values and expectations, for example acknowledging their own uncertainty, practitioners might prevent themselves alienating parents (Gergen, 2022). I have interpreted that parents in this research are asking for practitioners to focus on their interactions in a way that parallels transformative dialogues and their possible therapeutic effects, generating shared understanding through human connection, potential new meanings and a sense of optimism.

*5.3.3 Implications for practitioners and conclusions*

David, John and Kate are each going through the process of obtaining an EHCP for their children. They told me that they are applying to obtain funding to have an adult working with their children one to one and they welcome this support. School staff seem to have been proactive in the process of requesting a statutory needs assessment, following SEND CoP (DfE/DoH, 2015) statutory guidance as they have identified Maddie, Rob and Lee’s needs. However, it could be argued that funding for support as a result does not encompass cultural factors which go beyond welfare entitlement and which determine disability (Timimi et al, 2016).

Goodley and Roets (2008) write that different models of disability need to be taken in consideration when meeting the needs of children with disabilities. David, Kate and John have indicated in their narratives that they value having relationships of trust with practitioners, which can help them process emotions of loss and grief while respecting the preciousness of their children. Developing guidance and understanding among practitioners of the relevance and potential benefits of these relationships might help them to work more collaboratively with parents, which is also stipulated by the SEND CoP (DfE/DoH, 2015). By becoming more familiar with the concepts of containment and intersubjectivity and applying ways of working conducive to mutual understanding, such as Gergen’s transformative dialogue, it might be possible to help redress shortcomings researchers have noted in the way statutory assessments are carried out and written, such as focusing on within-child deficits instead of being person centred (Cochrane & Soni, 2020).

**5.4 What is the role of the EP in supporting parents of children with SEND in the EY and in supporting practitioners to learn from parents’ accounts of their mutual interactions?**

*5.4.1 Widening the paradigms applied by practitioners*

Fox (2011) argues that EPs need to take the perspective of “practitioner researchers” in order to be able to apply a broad range of theories and paradigms to problem solve situations that seem to be stuck (p 328). This research has helped me to adopt this approach, leading me to conclude that educational psychologists could broaden the discourses on disability and child development they use and help other practitioners to do the same. A possible way of doing this might be to make better use of CDS, which problematises the concept of child difference and questions societal practices to wonder how they can be changed for the better by disability (Williams and Goodley, 2017). Curran and Runswick-Cole (2014) bring to the mixture DCS, which shifts away from normative child and deficit discourses to view disabled children “as having childhoods, not problems” (Curran & Runswick-Cole, 2014, p 1617). My research suggests that educational psychology practice needs to go beyond intervening at an individual level to share these paradigms with other practitioners and promoting an open debate in society on the constructed nature of disability and child development. EPs have the potential to promote a human rights perspective and thereby reduce the stigma and blame being experienced by parents like David, John and Kate. As a result, parents would not have to either ignore their child’s disability to overcome the stigma it might generate for them or worry about the stigma that it might bring to their child or embrace labels to shift this stigma, sometimes entering a dynamic of “fighting” with practitioners in order to secure early intervention.

*5.4.2 Applying psychoanalytic concepts in EP practice*

Billington (1995) proposes that discourse analysis can reveal aspects of individuals and also structured social positions and power relations. In this research I have applied concepts from Lacanian discourse analysis to interpret the multiplicity of meaning in the parents’ narratives. Therefore, I have interpreted meaning in the words used and also meaning implicit in the “sliding of signifiers” to hear the Symbolic Order, the social, in the narratives. This allowed me to appreciate the complexity of the narratives and apparent contradictions, such as the fulfilment parenting their children has brought to John, Kate and David whilst also creating meanings associated with loss and uncertainty, and the way in which all of these narratives are influenced by culture and their individual contexts.

Lacan’s concept of the mirror stage has also been helpful in explaining situations in which parents feel distress because the way they behave or see themselves is not in tune with the image they have of how they ought to be, for example, when Kate insists she does not want to be “a pushy parent” (line 24) but she is pushing to help her son. I think that applying Lacan’s work to attend to meaning in the conversations with CYP, parents and other practitioners could also be helpful in educational psychology practice. Billington (2006a) proposes that applying Lacan’s model of discourse analysis to EP practice would mean attending to the complexity of social processes taking place during interactions instead of focusing on the relationships between signifier and signified, which according to Lacan, cannot capture this complexity and might lead to reductionist interpretations of language (p 74).

Kate, David and John seem to highly value having relationships of trust with practitioners. Educational psychologists are in a privileged position, due to their knowledge of psychoanalytic concepts and relational psychology, of being able to help practitioners to build these relationships, for example, by supporting them to become familiar with the concept of intersubjectivity and to enable them to facilitate holding environments and containment of emotions.

Kennedy and Eastwood (2021) give examples of how a psychoanalytic approach to assessment can be implemented in EP practice by considering assessment a therapeutic intervention and using projective techniques, such as the Dynamic Family Drawing, to generate hypotheses on possible ways forward in addressing the problem presented, which can be tested in school or by the child’s parents. Consultation and supervision might be two obvious fields in which psychoanalytic theory can help EPs. For example, Eloquin (2021) advocates for the use of Klein’s theory of objects and part objects in consultation to help practitioners see ‘the whole object’ when they focus on a problem without taking account of other aspects of the child’s life which might help in finding ways forward. Also, consideration of defence mechanisms, such as transference, countertransference and projection during a consultation can provide valuable information to the EP on the consultees’ experience of a problematic situation (Eloquin, 2021). Shaldon et al (2021) also describe the Relational Model of Supervision for Applied Psychology Practice to illustrate how psychoanalytic, systemic and attachment theory can guide supervision in EP practice.

*5.4.3 Coproduction between practitioners and parents*

The parents in this research valued being listened to, and instances in which they felt this was not happening created anxiety and frustration. It is appropriate to draw upon the Frankfurt School postulate that collaborative working with marginalised groups is necessary to accomplish social change (Howell, 2013). Coproduction is described by Bell and Pahl (2018) as genuine collaboration, where everyone has a voice and, according to Anderson (2009), a values-based philosophical stance is needed for practitioners to work in this way by “connecting, collaborating and constructing” meaning with others. Billington (2000b) also describes the potential of coproduction to empower families of CYP with SEND while working with practitioners and, crucially, to prevent harm that practitioners can exert by taking on the position of experts. Educational psychologists, in promoting collaborative working with parents as set out in Chapter One of the SEND CoP (DfE/DoH, 2015), are well-placed to aid a problem solving dialogue, for example, Gergen’s transformative dialogue (Gergen, 2022) and further develop theory and practice in this area.

*5.4.4 The role of educational and child psychologists in the early years*

Although EPs can support planning and the reviewing of early years services (Wolfendale & Robinson, 2001), my experience working as a trainee educational psychologist is that most educational psychology practice in the early years seems to be confined to conducting individual statutory casework (Douglas-Osborn, 2017). This research supports previous studies’ findings indicating that educational psychologists have a role:

“...supporting staff to avoid excessive individualisation of children with special needs, moving away from a “within child culture”, towards a more inclusive environment” (Dennis, 2004)

In this research, parents’ adoption of the grand narrative of child development in which children are supposed to progress according to a predetermined trajectory from birth to adulthood, does not take into consideration alternative, socially constructed, models of child development. EPs are able to challenge this view and have a role in sharing more inclusive perspectives with parents and fellow practitioners across disciplines.

*5.4.5 Applying an intersectionality framework in practice and research*

Strier and Perez-Vaisvidovsky (2021) discuss that theories of fatherhood are based on “middle-class, Anglo-centred, dominant, and mainstream” fathers, while other groups remain “undertheorized” (p 334). This has implications for practitioners because they might not be as aware of fathers’ experiences of caring for a child with a disability in order to help them feel accepted in this role. Considering the gender of the parents whilst analysing their narratives in this research has helped me to gain a better understanding of how it might influence the meaning they give to their experiences, for example, attending playgroups. I think this has been valuable in bringing to my attention the inadequacy of generalising hegemonic views of masculinity and fatherhood, as here, alternative voices have been heard. This understanding can be attained in educational psychology practice by applying an intersectionality framework and bringing this to the attention of fellow practitioners, making it necessary to take into consideration individual social characteristics to be able to appreciate their experiences (Crenshaw, 1998).

**5.5 Limitations of this research**

In this research, by applying narrative methodology, I have explored the meaning parents give to their interactions with practitioners. I have applied reflexivity to identify the ways in which my subjectivity might have influenced the research. As a result, I acknowledge that the narratives told have been co-constructed and influenced by my subjectivity, and that of my participants, and so they have become one possible interpretation of the narratives intended to be told. For example, while I interviewed the parents my utterances might have influenced theirs, and the discourses in which I am immersed, in turn, might have influenced my analysis of the narratives. In order to attend to these shortcomings, I have striven to anchor the research analysis to the text and provided full transcripts of the interviews in the appendices.

I have acknowledged that this research involves a very small sample of parents recruited in a specific context. Therefore, the aim of this research is not to generalise its conclusions to the whole population. However, the learning from qualitative research involving a small number of participants or case studies has been, and will continue being, helpful to practitioners by transferring the theoretical propositions of the research (Riesman, 2008, Wells, 2011). For example, the implications for EPs proposed in this research can provide ways forward to practitioners in situations in which they feel “stuck”.

Another point to take in consideration is my position as a practitioner, which highlights how power imbalances between me and my participants might have influenced the narratives they shared with me. I think being the researcher also endowed me with power as I was the one setting procedures and time schedules. However, I tried to overcome this limitation by giving the parents choice as to where to meet, the format of the interview, face to face or online. I was also keen to make the telling of the parents’ stories a positive experience for them so I hope I came across as approachable and friendly.

**5.6 Recommendations for future research**

This research indicates that parents value having relationships of trust with practitioners, which are characterised by the practitioners showing understanding of their experiences, and being transparent about their own vulnerabilities, enabling problem solving and coming to possible ways forward together. The analysis of the narratives suggests that when relationships are established, interactions can provide containment for parents’ emotions but they can equally become a source of distress when parents feel they are unheard. Further research on how to build relationships of trust by bringing to the forefront of practitioners’ practice the psychoanalytic concepts of containment, intersubjectivity, Lacanian discourse and social constructionist approaches, such as Gergen’s transformative dialogue (Gergen, 2022), might support current efforts in SEND policy to facilitate coproduction with parents to be able to create new meanings together.

If there had been time within the current study, I would have liked to have carried out action research to incorporate the parents’ voices on the research analysis and conclusions. This would have increased their agency in the research and perhaps provided new insights into their experiences, also addressing any limitations created by power differentials between them and myself as the researcher.

I feel it would also be of value to study parents’ interactions with practitioners as their children grow up to identify how their narratives are influenced by changes in their context, such as starting school. This might also shed light on how parents’ perspectives on ways forward available, such as diagnoses and EHCPs, might change in time. Additionally, further research on intersectionality including gender, social background and disability, could also help identify the influence of these factors on parents’ experiences.

**5.7 Conclusion**

In this research I have explored the meaning parents of children with special needs in the early years give to their interactions with practitioners involved in their children’s lives. I was interested in learning about which practices might be emancipatory or oppressive for parents and how practitioners can improve parents’ experiences given my own personal and professional experiences of Western education, and the shortcomings in the current SEND system identified in the literature, for example through the recent DfE SEND review (DfE, 2022). Within the narratives studied, parents hope that their children will be able to communicate, have positive interactions with people who are friendly to them, and have fun. There seems to be anxiety about the uncertainty for their future and the possibility of their children being rejected and misunderstood by others as a result of their way of being. Complex emotions of self-blame and loss mixed with joy brought by parenting their children are highlighted. Parents seem to be markedly influenced by cultural discourses, including within-child deficit and pathologising discourses, the notion of ‘normal child development’ and Western narratives of parenting. As a result, they seem to have found different ways of becoming good parents, such as seeking a diagnosis, pushing for practitioners to help their children or ignoring their disability. I argue that these dominant cultural discourses do not meet parents’ hopes, which seem to contain a call for inclusive education.

The parents involved in my study appear to value having relationships of trust with practitioners who are able to contain their emotions, supporting the need to broaden discourses around disability and child development. As Curran & Runswick-Cole (2014) note “...spatial, social, cultural and economic dimensions of children’s lives” need to be considered to improve the experiences of people with disabilities (Curran & Runswick-Cole (p 2014, p1626). This has implications for educational psychologists, who are well placed to help other practitioners reflect upon, and bring about, emancipatory practice embodied in genuine collaborative work with parents and a human rights approach to difference. Timimi (2016) proposes that such an approach can “...eradicate discrimination and improve social inclusion across the board” (Timimi, 2016, p 29).

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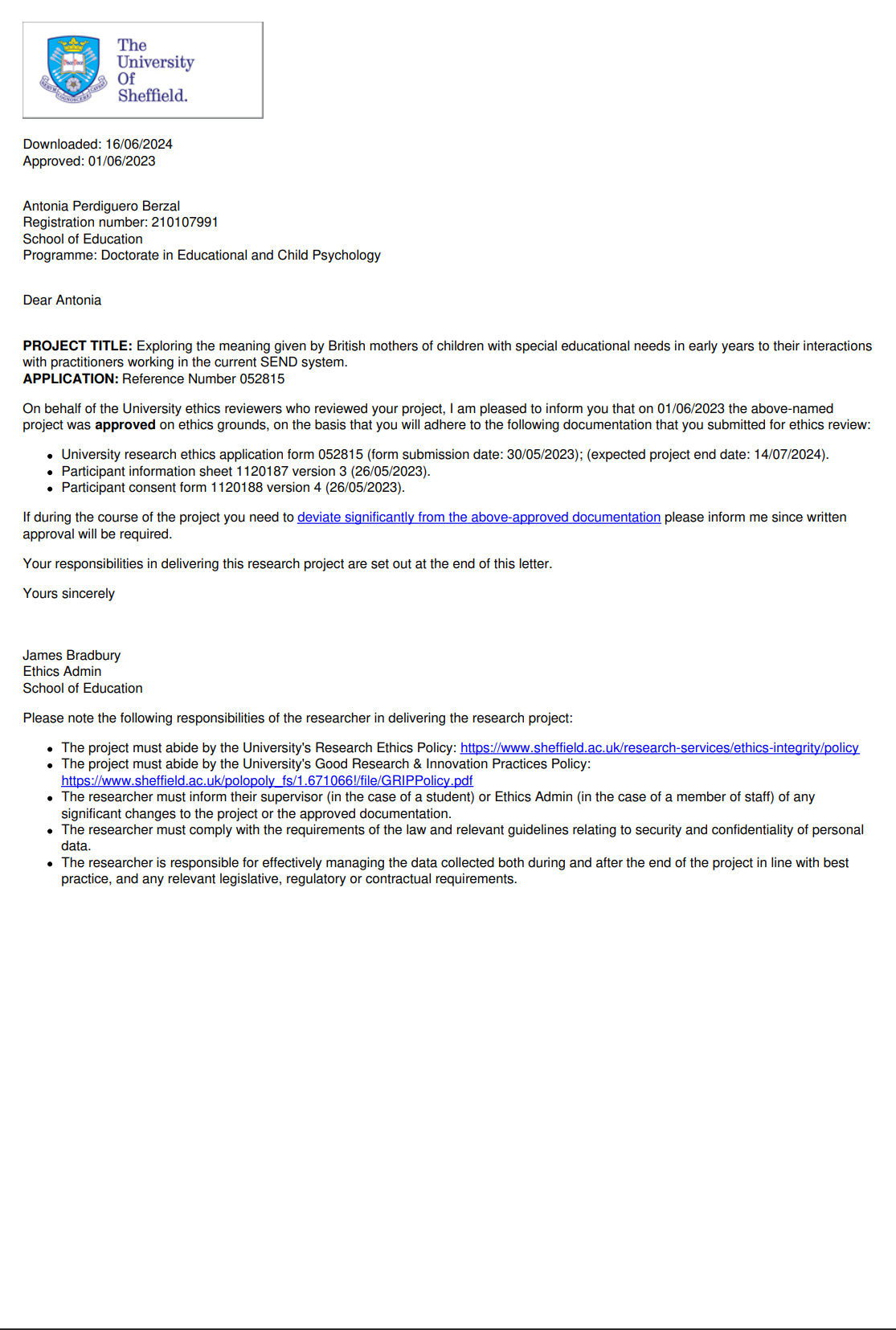
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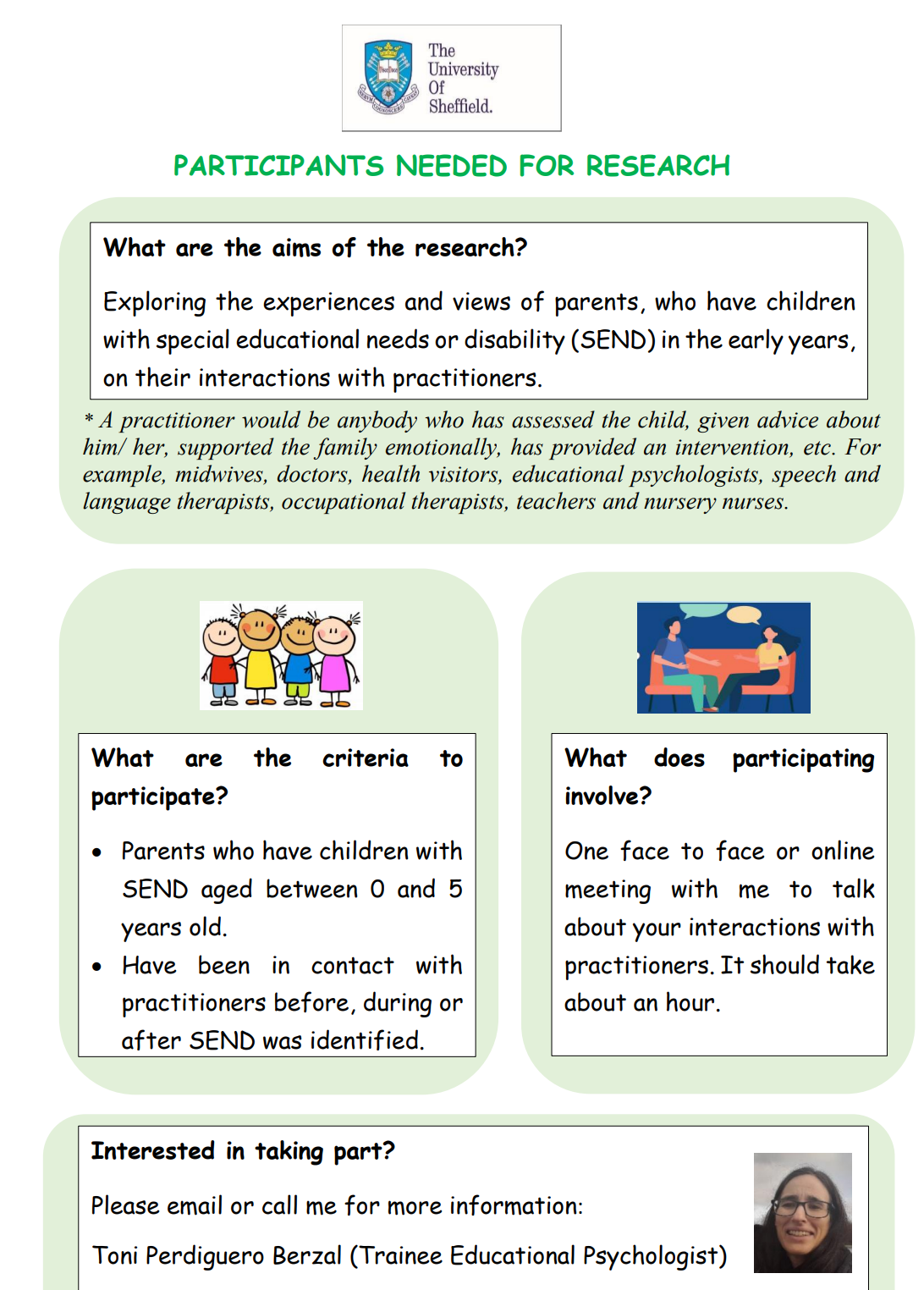
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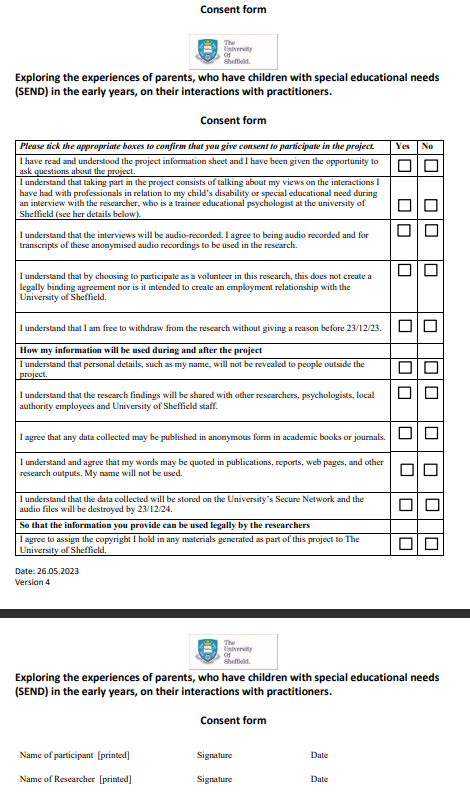
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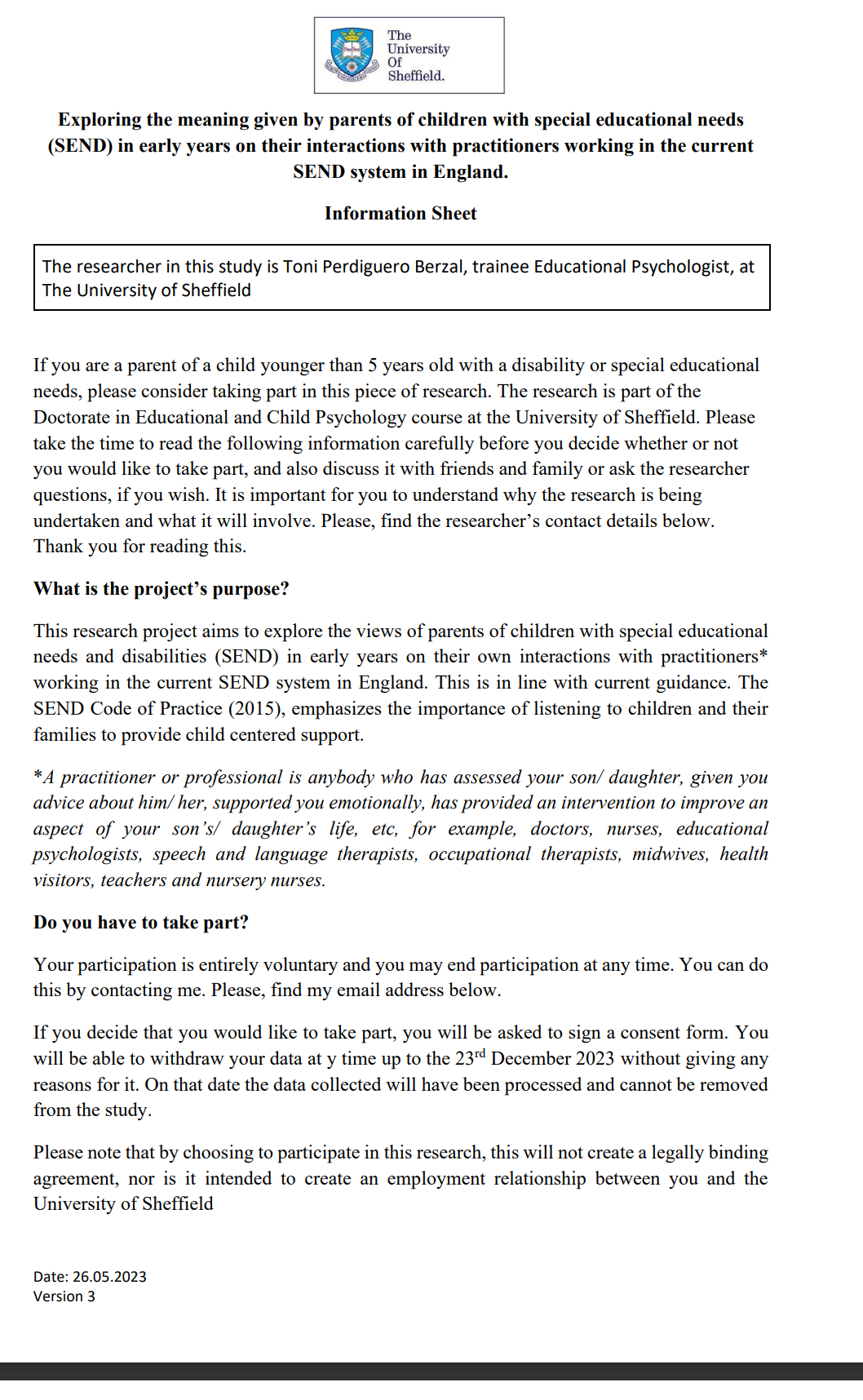
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**Appendix 2 Research poster**

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**Appendix 3 Consent form**

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**Appendix 4 Information Sheet **

**Appendix 5. John’s transcript micro and macroanalysis**

**Part 1 groups and nursery**

**Strophe 1:** groups

**Stanza 1:** introductory question about interaction with practitioners.

1. **Toni:** Thank you very much for being here John.
2. Mmm… I am sure it is working.
3. So, yes, could you tell me about your interactions, the contact you have had with practitioners regarding your little girl, regarding Maddie
4. So practitioners could be the nursery nurses, the doctors, paediatricians, nurses, psychologists, the speech and language therapist, people in FA also.

**John**: Yea.

1. **Toni:** anybody really/ *And it could* be in any order.
2. I do not know Maddie at all so if you could give me a little background (.) of what she is like that would be great.

**Stanza 2:** frequency of the groups

1. **John**: She started going to a *FA group in BI*/ when she was (1) I want to say (1) 5- 6 months old.

**Toni:** ok

1. **John**: I think it was just a *morning*, I think it was a morning session

**Toni:** right.

1. **John:** It was L L I think *it was called* and she used to go there
2. but there were *kids* there who had disabilities as well

**Stanza 3:** age

1. and *Maddie* was there but Maddie was like an older, she was like an older/ she was the oldest one there so we could only go for (.) ahh, 4 months/ because when you *hit* (.) I think when you hit 1, I think you weren’t allowed.

**Toni:** [1 year old]

**Strophe 2:** starting nursery

**Stanza 4:** timings

1. **John:** you then have to go to a different one/ but when she hit 1 we started to get her in/ she was in *school* an afternoon only 2 days/ but now she is in every morning

**Stanza 5:** coming on by being able to communicate

1. and she is come along
2. like (1) before she went to school she (.) *couldn’t* (.) *speak*
3. she is non-verbal as it is now/ she doesn’t talk
4. but she’s come along/ she knows sign language

**Toni:** wow

1. **John**: she (.) ah, she *knows* (.) what she wants/, she will *take you* to what she wants. She, she shows us pictures, she knows what they are but/
2. obviously she can’t speak/ because she is *non-verbal/*.
3. She is in, she’s got routines from school
4. but school helped her lots, *absolutely lots.*

**Stanza 6:** nursery structure

1. **Toni:** for how long has she been going to school?
2. **John:** I think since she was seven months old
3. ‘Cause it’s a *private* (.)/ so she went to the baby room and then she went to this (.) it’s called */*  it’s around the corner/. She goes there/
4. and they have what they call the *Nest*/ so it’s where they have the babies (.) I think (.) since they are 2 months old to one year old
5. and then (.) from the age of one you go to the other side
6. and she’s come on leaps and bounds in there. Absolutely loads!

**Part 2**: **special needs identification**

**Strophe 3:** identification

**Stanza 7:** John’s diagnosis

1. Toni: ah fantastic (little laugh) (1) so, have you always known that there was a special need or there might be a special need?
2. **John:** I think there are (?) that are *mine*./ I’ve got ADHD, autism, dyslexia and dyspraxia and Aspergers

**Stanza 8:** uncertainty

1. So when it got (?) with Maddie,/ they looked at my history as well and they said there is a *30% chance* it could have something *wrong* in a girl (.)
2. **Toni**: that is very specific
3. **John:** And I think it was 70% chance in a *boy*.
4. It is more common in *boys* than it is in girls.
5. So we *knew,* we kind of knew, there was going to be something/ but we weren’t too sure what/ how *severe*

**Strophe 4:** John’s family

**Stanza 9:** diagnosis in John’s family

1. because it runs in my side of the family/ it runs in my family.
2. I am the worst in my side of the family.
3. My sister, she’s got a girl and (1) she got diagnosed (2)/ I think she got diagnosed with (.) I think it was *autism* when she was 7 or 8
4. so she was later on.
5. And she is not as bad as she was/ she’s come up a little bit but she’s still *bad* but

**Stanza 10:** John’s mum

1. (1) Maddie (.) cause my mum has seen it with me./ She’s dealt with it with me (cough).
2. When Maddie was born and developed after 1 year old/ my mum’s seen me in Maddie but *twice* as bad/ so my mum said to us she thinks there is something there.

**Strophe 5**: practitioners

**Stanza 10**: health visitor

1. And when she had the 2 year review the ah district nurse said/ sorry the health visitor said/ she can see she’s *definitely got sensory needs*.
2. She wasn’t too sure about the autism but definitely she’s got *sensory needs*

**Stanza 11:** paediatricians

1. and then, when we went to see the paediatrician in June, just gone.
2. He diagnosed with autism and severe sensory needs.
3. So *we knew*

**Strophe 6**: feelings about diagnosis

**Stanza 12**: a relief to have an explanation for others

1. (1) it was kind of (.) I kind of (.) I said to you (.) it was kind of a *relief*.
2. I know she is not/ (1) cause people look at her cause she has kick offs in like town and everything
3. (.) and people just stare.
4. Then (.) they don’t know to say something to you or not and then some people say to us (.) what’s up?/ I said “I don’t know”/ but *now I can say*.

**Stanza 13**: a diagnosis is more than a label

1. Someone told me the other day: is there anything…?/ Does she have disabilities?
2. Now I can say yea/ she’s autistic and sensory needs so
3. (.) that’s kind of (1) it’s like a *label* but it’s not, *it’s more*.
4. There is a diagnosis of why she’s like she is/. She is not just a naughty child.
5. She is (.) there is something mentally wrong with her.

**Strophe 7**: clarifying why a diagnosis is a relief

**Stanza 14**: when I was a kid, you were just a naughty child

1. **Toni:** You are telling me that it is positive to have an explanation?
2. **John**: It is, I think it is. It is *positive* to have a label because when I
3. (.) *I’m 28 now*
4. (.) so when I was a kid there was *nothing* like this around.
5. You were just a naughty child.

**Stanza 15**: now it’s come on leaps and bounds

1. But now, I think it’s come on *leaps and bounds* from when I was a kid.
2. Now (.) it’s (.) I think you need to have (1) a label cause then people don’t (.)/ People assume you just have a naughty child.
3. But then, if you got a label and you can say/ (.) they think I shouldn’t really say *that*
4. cause (.) it’s (1) I mean (.) it’s not (.) you are never going to get rid of it/. It’s a mental disability.

**Toni**: yea

**Stanza 16**: John’s experience of his diagnoses

1. **John**: I’ve known it 27- 28 years of my life/.
2. I’ve got diagnosed/ (.) I think (.) I was born with ADHD, I was diagnosed with autism at 4 and I’ve been on tablets since I was 5.
3. So I am on *sleeping tablets*, I am on day tablets
4. and *people say* how do I *deal with it* on a day to day basis.
5. Some days I have good days/ some days I have *really bad days* and I can’t go out of the *house* (.)/ I have to stay in the house but (1)

**Part 3: family support**

**Strophe 8:** The understanding of the family

**Stanza 17**: N’s understanding

1. but my wife, she is a carer/. She deals with it
2. (.) she looks after people with severe ADHD and autism/. She works in a residential home
3. so she, she knows the adult side but she doesn’t know the child side because she only has dealt with adults
4. so, ah, she (1) In Maddie’s head and my head (.) my mum says I know what Maddie is thinking because *I’ve got it*/.
5. But *N* (.) N struggles sometimes because she doesn’t understand what Maddie wants where sometimes I do/ cause I was like that at one point

**Stanza 18:** John and N help each other.

1. so it’s kind of, ahh, she’s helping me because she’s dealt with it/ and I’m helping her cause I’ve dealt with it *all my life* and my family has

**Stanza 19:** differences between John’s and N’s family

1. so (.) my family is my support as well/ (.) my mum, my mum is mine and my wife’s support cause her, my wife’s side, they don’t have disabilities in their side of the family/.
2. Maddie is the first one/ the first grandchild who has got a disability
3. but obviously in my side we’ve dealt with it (.) with me for 28 years so,
4. *my family is my support*
5. they don’t (.) they (.)/ I couldn’t, with N’s mum and dad I could leave Maddie, they are *brilliant* with her, on her side
6. but *on my side is more/* (.) I don’t want to say they are *more better* but they *know more* of what Maddie is going through because they dealt with it.

**Strophe 9:** John’s family. Reasons for the role of John’s mum.

**Stanza 20:** John’s mum support

1. **Toni**: there is more understanding
2. **John**: Yea, there is more understanding/ but *my mum* is, ahh, both of our supports.
3. She’s been *amazing*
4. Like she comes to appointments with me

**Stanza 21:** John’s grandad passing

1. because my nana/. I used to live, ah (1), I used to live with *my nana and my grandad* so (.)/ cause I *never* had a father figure in my life so my grandad
2. he passed away in March this year

**Toni:** (low voice) [sorry to hear that]

1. **John**: So he was kind of like *my dad*/ and my nana/ I was really, *really close* with them/.
2. So when they passed away, ah (1)/, it was kind of a *shock*/

**Stanza 22:** John’s family support when he was a child.

1. so (.) cause when I was a kid my mum and nana/ (.) My mum used to go to see my paediatrician quite a lot
2. so *my nana was as well* cause we used to live with my nana.

**Stanza 23:** John’s mum understanding

1. So my mum is kind of doing the same thing where I go to the paediatrician/ but my mum wants to come as well because she is /(.) kind of what my nana was to Maddie now/
2. *so she comes to everything*.

**Toni:** right

1. **John:** Every appointment to do with Maddie and her disabilities my mum is there.
2. so she asks (.) She has *more of an understanding/*. She asks more questions than we do. She is like (.)
3. **Toni:** She knows what she is looking for, maybe?

**John:** yeah, she does yea

**Part 4: practitioners’ support**

**Strophe 10**: paediatrician’s appointment

**Stanza 24**: it was absolutely brilliant

1. **Toni:** And what are the appointments with the practitioners like? I mean, if you go to the paediatricians how was that?
2. **John:** oh, it was *absolutely brilliant*

**Toni:** yes

1. **John:** so we went in and (1)/ there was toys everywhere and she was (.)/ he listen to her heart because she was born with *a heart murmur*

**Stanza 25**: paediatrician followed Maddie’s lead

1. ah (.) and the stethoscope *she wanted* so he gave it to her
2. and he played *with her*/ He didn’t tell her to sit down.
3. She went around the room and did *what she wanted*.

**Stanza 26**: telling ‘no’ to Maddie

1. If she wasn’t allowed or something, obviously, we told her ‘no’ cause obviously she was at the doctor’s desk and she wanted to draw but he gave her some stuff to play with and it was
2. (.) If she didn’t stay there and he needed to examine her/ *he followed her around the room.*
3. It was absolutely brilliant with her, *absolutely brilliant*.

**Strophe 11**: remembering who said what.

**Stanza 27:** unable to remember.

1. **Toni:** fantastic. That is really nice to hear actually/. Just, going back to what you told me that someone told you that there were 30% possibilities that something would be wrong/, when did they tell you and who was this?
2. **John:** ah (3) I really can’t remember now*/. I am sure* someone told us/ (.) I don’t know if it was a doctor or someone but someone told us that there is more change if it’s a *boy* than if it’s *a girl*/ and they did, they said a percentage but I can’t/ I am not too sure of who
3. **Toni:** You are not sure if it was a practitioner or maybe it could have been someone…

**Stanza 28:** I don’t think it was a practitioner

1. **John:** I don’t think it was a practitioner/

**Toni:** ah, ok, ok/

**John:** I don’t think so. I am not too sure/.

1. **Toni:** ok, that’s fine… ok… yea/
2. **John:** no, I don’t think it was actually (2) to be fair/ I can’t really remember who it was that told us
3. **Toni:** so it might have been someone
4. **John:** I think it might have been *someone*/ (.) someone said something to us I have obviously
5. (.) I thought it was a practitioner or something but I am not 100% sure/. *I don’t think it was* actually.
6. **Toni:** That's fine, that’s fine (low voice).

**Strophe 12**: resources available outside nursery

**Stanza 29**: groups and nursery as providers of information

1. So you have had all these appointments with doctors, etc,/ eh (1) what about, what about emotional support and continuous support, is there enough/ (.) I don’t know you went to (.) L L?/ Maddie was going to L L, is that for children who have special needs? /
2. **John:** *noo* (.)/ as I said *any baby* up to I think 1 can go there
3. (1) it’s not (.) it’s like
4. I think Maddie is *the only one* is mainly for children with/ (.) cause we found that *with school/* which is for children with disabilities or children who are *getting diagnose* with disabilities
5. so that (.) she *loves* going there.
6. She knows on Wednesday she goes there from 1 till 2 o’clock on Wednesday. She knows she goes there on Wednesday/ and it’s just (.) I think it’s more (.) there is more

**Stanza 30**: information and courses available on autism

1. (.) We are going to do a course with AC/. When the kids go back/ (.) It’s an autism course over W/ I think me and my wife we’ll do that.
2. I think there is *more stuff around* now/ As I was saying, there is more stuff for children with disabilities *now* and courses than there was/. There is a lot more information about

**Stanza 31**: difference between the present time and John’s childhood

1. cause I didn’t know when I was growing up/ but the spectrum now it’s absolutely ma-*massive*/

**Toni:** yes, yes

1. **John:** you can’t be (.)/ cause obviously when I was growing up it was just you were *autistic/* but now (1) the ADHD, the Aspergers… it *all comes under* autism, now, I think

**Toni:** yea, yea

1. **John:** But when I was a kid, it wasn’t/. They were their own labels
2. so now I realise… (Interruption by John’s watch telling him how long he had walked for. Toni laughs)
3. **John:** there is actually a massive (.) sorry (.)
4. **Toni:** don’t worry
5. **John:** there is actually a *massive* spectrum of autism and I think that has come along leaps and bounds as well/ cause we always had

**Strophe 13**: applying for support at nursery

**Stanza 32**: the SENDCo is requesting it

1. (.)/ the school Maddie is in (.) is a big help (.)
2. they’ve got a couple of kids there that actually got disabilities/ and we are just going through about getting the (.) I think the SENDCo is coming in September to see about one-to-one hours for Maddie

**Toni:** right

**Stanza 33**: reasons for requesting the support

1. **John:** because they think she will need *one to one hours*
2. because some days she (.) we’ve been a *couple of times* we had to go to pick her up/ because she’s too much for them *to handle* with kick offs and anything like that/ so we’ve actually had gone a couple of times to pick her up (cough) to get her/ and, ahh, it’s like (.) some days (.) sometimes (.) it’s like (.) err (.) it’s like (3) I don’t know

**Stanza 34**: looking at the child’s needs

1. (.) It’s the same with the courses, there is a lot more to do with *autism*/ but it’s not just autism/ it’s for the whole thing

**Toni:** [for all special needs]

1. **John:** it does *not just specify* on the one disability (.)it’s the whole disabilities
2. and that’s what I like about them
3. ah (.) The paediatricians as well/. They don’t just (.) When you go, they do *not just look at one thing*, they look at other things (.) they say I’m not just looking at if she’s got autism/. They look at *everything* on the autism spectrum: the sensory needs, the autism, stuff like that
4. and that’s what I like about them now.
5. It is really, really good and I said that paediatrician was *really, really good*

**Stanza 35**: nursery being proactive leading the process

1. **Toni:** that’s really good to hear
2. eh (.) so about the school, they might be applying to get some more support so, do you know what the process will be or are you quite confident that the school will help and will guide you?
3. **John:** Oh, yea. I think they’ll help
4. eh, we went before she finished school on Wednesday (.)/ I think a couple of weeks before/ (.) we had a video call and we went through some paperwork to look at/ (.) to actually get her the one to one hours and stuff like in the school (cough)
5. but I think… I think I am *confident* they would (.) If we didn’t say/ because we didn’t say she needed the one to one hours
6. the school came to us and *asked us* if it would be ok for them to apply for one to one hours/ cause they think that she does need the one to one hours.
7. **Toni:** Yes, so that is helpful?
8. **John:** Yes, it’s really *helpfu*l, it is really helpful/, just to get her some more support and
9. (.) cause they said the one to one hours, whichever school she goes to now apparently she will get funding for cause she needs a support worker/ (.) apparently will get funding for that support worker/ because *she needs* those one to one hours.

**Strophe 14**: what helps interactions with practitioners

**Stanza 36**: support for children in local groups

1. **Toni:** right, fantastic/ so… yes… again going back to… to interactions with practitioners/ (.) I mean you had also health visitors involved (.) so what helps/ (.) you were happy with the paediatricians/ (.) what *helps* those interactions/ also FA/ what supports you? What *is goo*d about it?
2. **John:** ahh… I think the good with FA is that you’ve got the support there if/ (.) It’s like there is a Facebook you can go to (.)/ there is people you can go to and ask questions/ and (2) if you don’t know something you can ask them
3. and eh (.) I think that the main support for (.) autistic children is, in B, is FA.
4. They do loads of stuff, absolutely loads during the holidays.
5. We did know about the M but apparently there is *more stuff* they do over the holidays/ to keep

**Stanza 37**: importance of routine

1. (.) I think is to keep children in the routine they’ve got
2. cause if Maddie *comes out* of her routine, she has a kick off and a meltdown and if she’s not in the same routine every single day she has a *kick off*
3. so we’ve got to plan like/ sometimes two weeks in advance/ *whatever we're gonna do*/ So take her out of that routine 2 weeks before so we know that she’s all right for the week after/. We always have done.
4. **Toni:** So you understand that is what she needs.

**Strophe 15**: support for parents

**Stanza 38**: it could be better

1. Emm what about for the parents? What about for you and your wife, is there enough support for the parents?
2. **John:** ehh (3), I think *there is* but I think it could be done a little bit
3. (.) because obviously with Maddie as it is now (.)/ cause as I was growing up my sister was going to, like the (3) I cannot remember what’s called now
4. **Toni:** don’t worry if you cannot remember the name
5. **John:** something for carers/ (.) that’ve got brothers or sisters with disabilities/ (.) *Young Carers*
6. They’ve got (.) like you can only go to a certain age

**Stanza 39**: there is no respite for parents

1. where (1) it’s like (.) I don’t think there is anything that/ (.) if Maddie does get worse there is no/ (.) I don’t think there is anything that I can, we can take her/, we can leave her just to give us a couple of, just to
2. **Toni**: [just a respite]
3. **John:** just *a couple of hours*, just *to ourselves*.
4. I don’t think because of her age, I don’t think there is anything for that age/. I think it’s more, eh, older kids that/ eh, just like (.) I don’t know where there is anything/. It’s just I think it’s for the older kids/, not *the younger ones/*, like the baby kind of things/.

**Stanza 40**: family provides respite.

**Toni**: yes

1. **John**: cause some days (1) with our respite/ (.) we have my family and her family
2. some days we can phone my mum and she will come and me and N can go out just for a couple of hours/ or just stay at home and watch a film/ or (.) it’s just to have that time just for me and N because we are dealing with

**Stanza 41**: people don’t see what happens behind closed doors

1. (.) *people don’t see* what happens behind closed doors with *Maddie*/. The times she is out she is the *happiest* (.) kid
2. but sometimes she couldn’t be
3. and then they say why she doesn’t have a pram and stuff like that/ (little stammer) It's because if she comes off a pram and she does not want to get back she kicks off
4. but then when we get home/ she hits us, she slaps us, she
5. people don’t see what happens behind closed doors/. It’s always (.) they always see what happens out the doors.

**Toni**: yea

1. **John**: where she is always her happy, normal self
2. **Toni**: yes (1) yes... I suppose that people play a big part on the carers wellbeing, don’t they? because they might be feeling a bit judged I think

**John**: yea

**Strophe 16**: waiting times

**Stanza 42**: timeframe to see practitioners

1. **Toni**: eh (.) so focusing on practitioners, what, eh… Is there anything that hasn’t been so supportive?/ You have been very positive about them and how things have progressed with the years but is there anything you can think: well, this wasn’t, wasn’t really a good experience?
2. **John**: I think it was the *timeframe*

**Toni**: right

1. **John**: because we got on (.) obviously the health visitor came out when Maddie was one (under his breath: was she one?) No, 2, she came out when *she was 2* and she obviously said/ I am going to send (.) I’m going to ask the paediatrician to send an appointment *for ya*/ so we got a letter/, now, we got a *phone call* to say there will be an appointment coming for *Maddie*, we just don’t know when and that was *October last year* (.) so it took from October last year to June this year just to get an appointment/ so I think that is the only downfall.
2. It’s the waiting times at the minute/ cause obviously we’ve been to see the paediatrician/. Now, we are waiting for everything else and the speech and language (.) they said, like/, there is a *6 months waiting* for speech and language and everything else.
3. I think it’s just the waiting times/, it’s *not as good* as it probably can be.

**Stanza 43:** what could be done.

1. There could be *more* paediatricians and stuff like that/ (.) because we actually didn’t go to the hospital to see the paediatrician (.)/ we went to the one in A/ cause apparently you can only go to the one in the hospital if you have been diagnosed/, where you’ve got to go to this one to get a diagnosis/. I think that’s a bit/ (.) you should be able to go to any (.)
2. not to like go straight away (.) just to cut the times down a bit/ because I know people who have been waiting two and a half years now/ just to get an appointment/.

**Toni**: [(inaudible) It is…]

**Stanza 44**: resignation

1. **John**: It’s just one of them/. I think it’s just the waiting times for everything/ (.) to see someone/. And now we are just waiting for letters/, ehh, *speech and therapy* and stuff I had to get through/ It’s just the waiting times that are *terrible*.
2. **Toni**: yes, yes two years it’s (.) definitely *too much*.

**Strophe 17**: financial pressures

**Stanza 45**: need for diagnosis to go to places

1. Eh, ok, once you have seen the paediatrician, you have already told me it’s a relieve to have a diagnosis,
2. is there anything else you can think of that you might need for Maddie and maybe it’s not available/ or for the family, for you and your wife also.
3. **John**: eh (2), I’m not (3) (quietly) to be fair/ I think it’s like I said with the waiting times/. Now we are just waiting for a *piece of paper* to have Maddie’s diagnosis in a piece of paper
4. because some places/ (.) we are going to go away and stuff/ (.) but *some places* (.)/ because Maddie is classed as having a *disability/* she can go free to some places/ so like takes pressure off us because of the money side of things.

**Toni:** yes, yes

**Stanza 46**: each place uses its own discretion to ask for SEND proof

1. **John:** but the thing is some places, they need *proof,* but we haven’t got the proof/

**Toni**: ahh

1. **John**: We haven't got the proof yet/ but it’s (.) we don’t know when we are going to get the proof/ so it’s kind of one of them/. We want to take her to places but then we are going to still have to pay/ because she is technically (.) she’s got a disability but we’ve not got it in writing.
2. Some places only *accept* discounts if you’ve got it in writing/ *and we haven’t*

**Stanza 47**: missing out on things Maddie likes

1. and so sometimes Maddie has to miss out/. I’ve told my *wife* and Maddie to go and I’ve missed out/ cause sometimes we can’t *afford it* cause it’s… it’s
2. (.) sometimes during the holidays they do, places do like *deals/* some places, I think *B Zoo* is one (.)/ they are good with people with disabilities and stuff like that/. You don’t need, eh, *proof*, you don’t need proof to show that they’ve got a disability. You can just book. If they say, ‘does she have a disability?’ you *say ‘yea’* and you go.
3. The thing with Maddie is that *she loves* animals, absolutely she loves animals/

**Toni:** (quiet laugh)

1. **John**: So the zoo/ she is in her element in the zoo, absolutely in her element/. She loves animals, absolutely loves them/. She (.) she tries to mimic the sounds of the animals as well so she’s/ she just loves it.

**Strophe 18**: identifying special needs

**Stanza 48**: health visitor’s role

1. **Toni**: fantastic, so, going back to the health visitor that said “I will refer her to the paediatricians”/. Is that when you thought, yea, my mum is right there is something?
2. **John**: yea, when she said cause she said she’s definitely got *sensory needs*
3. but she said she’s going to refer her to obviously get a dia (stuttering) (.)/ just to see if she’s got anything else

**Stanza 49**: John’s mum and John knew.

1. and then (.) then I phoned my mum after it and my mum said: “*I told ya*.”/ And I said: “*You did*”/
2. so we *knew*. We kind of knew *then* that there might’ve been something (.) *there/*. In the back of our heads, in the back of my head I knew from the day she was born.

**Part 5: emotional impact of having a child with special needs on John**

**Strophe 19:** John blames himself

**Stanza 50**: emotional response to self-blame

1. I think there might have been something there because of *me* (.)
2. but sometimes I sit at night *crying* because I think the way Maddie is, I think it’s because of *me*/ cause I’ve got (.) I’ve got it/ so I think Maddie is like the way she is because of *me* (John has tears down his face).

**Stanza 51**: Maddie is gorgeous while acknowledging that bringing her up is difficult

1. **Toni**: John, I have met Maddie briefly and she is a gorgeous, gorgeous girl (sigh) and, eh, thank you for sharing that with me, eh… (quietly) You have a wonderful daughter/. She is wonderful.
2. I know that it is difficult

**John**: Yeah, it is.

1. **Toni**: because it will be difficult that she is different and people need to understand her/ and it’s (.) yes (.) getting on with *everything*/ that is a lot of *effort*/ to, to bring her up as happy as she can be
2. so you are doing *massive,* massive good work (sigh)

**Strophe 20**: fatherhood skills

**Stanza 52**: people’s judgement on John’s parenthood skills

1. John: yea, *everybody* tells me that cause obviously with (.) they say/, because obviously I’m dealing with it as well.
2. They are *amazed* at how well I’m dealing with *Maddie/*, bringing her up *as well*.
3. Sometimes I’ve got to have her on my own and they didn’t think I would be able to look after her.

**Stanza 53**: John’s self- doubt changed to amazement.

1. And I didn’t think *myself* I would be able to (.) eh, look after her myself/, but *oh*, I was amazed myself
2. but she’s just my double but a girl.

**Strophe 21**: N’s point of view

**Stanza 54**: N’s understanding has come on.

1. **Toni**: (quietly) right. What about your wife, does she see things in the same way as you or…
2. **John**: err (.) she does, yea (3)/ I think N has it a little bit harder cause obviously she hasn’t dealt with it before and I have
3. but she has *come on* leaps and bounds N as well.
4. She understands

**Stanza 55**: N’s attends training to know more about autism

1. (.) she does lots of autism courses with work/ so she goes on courses at work to understand/ and any autism course at work she *always* puts her name down for it./ Every single time.
2. So she’s gone on *three*/ and stuff from that she’s actually brought home
3. and it’s *helped* Maddie/ (?) and she’s actually helped Maddie a little bit at home as well.
4. **Toni**: Yes, I think it’s, yeah, having that connection with work/ and being able to access, eh, resources or some information through that/ *It must be*, it must be beneficial.
5. Is, is there anything I haven’t asked you that you would like to tell me about? Or (.)/ anything you can think of?
6. **John**: I can’t think of anything, no.

**Part 6: John’s relationship with his father and John’s desire to be different**

**Strophe 22:** a normal life for Maddie

**Stanza 56:** wishing for a normal life

1. **Toni**: no, ok/ (.) I’m just curious. What are your hopes for the future? What is the…
2. **John**: ah (3) I think it’s (.)/ I know everybody said this/ (.) Maddie have *a normal life*/. Not be ah (2) it’s (1)

**Stanza 57**: being different to my dad

1. **Toni**: It’s difficult to define normal.
2. **John**: it is/. It is difficult to define normal because obviously my upbringing with *my mum*.
3. I, obviously, my father wasn’t in the picture
4. So (.) but I said to N when I was going to have my child, I wouldn’t be like *my dad*.
5. Whatever my daughter/ (.) cause I’ve seen it/ (.) my father he didn’t (.)
6. I’ve got a sister as well so he was *more* for my sister than me because *I’ve got a disability*.
7. He didn’t /(.) in his head *he thought* I was just naughty/. He didn’t like that.

**Toni**: right

**Strophe 23:** John’s relationship with his dad

**Stanza 58**: disability is in my dad’s side of the family

1. **John**: cause he, cause obviously what I’ve got is hereditary
2. so my mum kept saying to him: “he hasn’t got it from me”/ because, obviously, my mum, my uncle and my aunty none of them from my nana’s side have it from that side so it’s got to come from my real dad

**Toni**: yea

**Stanza 59**: The views of John’s father on John and family dynamics.

1. **John**: but as I said he didn’t think there was anything wrong with me.
2. He thought I was just naughty
3. so I got pushed to the side
4. and my sister got *everything/* (.) anything she wanted, she asked for, she got while I didn’t of my father.

**Strophe 24:** celebrating my son or daughter

**Stanza 60**: acceptance of disability

1. So (??) I said to N when *we do* get pregnant, if it is a boy or a girl I’m not going to be like (.) whatever my daughter or son wants, they get.
2. I’m not going to put them aside *disability or not/*. They are still my daughter/ I look at them (.) I do not look at her as having a disability,
3. it’s just my kid.

**Toni**: yes

**Stanza 61:** I am going to love them and I don’t care about disability

1. **John**: I don’t care
2. (.) because they said (.) eh, as well to do the test for Down Syndrome
3. but I said to N they’ve given you this paper but I don’t want it/, I don’t want it/. I don’t care if it comes Down Syndrome.
4. I’m gonna love it/. I don’t care *what* it’s got or what is wrong with her, I’m still going to *love her*/, love the baby/. I don’t care.

**Strophe 25:** father- daughter relationship

**Stanza 62**: the bond

1. And *actually* she’s my (.) she’s on my hip 24/7

**Toni**: (quiet laughter)

1. **John**: she *cries* when I go out of the door and everything/. She’s my (.) from (?) she’s always wanted me, not N/. She’s my (.) she’s my baby girl.
2. **Toni**: You have a connection.
3. **John**: yea, we’ve got like a (.) It’s like father and daughter bond/. We’ve got *that*.
4. So she’s *always* wants me, it’s always me.
5. Sometimes obviously is N
6. but when she was born/ (.) her first word was *dada*, she always comes to me, it’s always me.
7. and it’s like (1) how I see it (.) it’s like P, my sister with my real dad/. That is the kind of thing.

**Strophe 26**: siblings

**Stanza 63**: John wouldn’t care disability or not. They are my children

1. When now it’s me/ but if I had another child I wouldn’t *push* the other child out/. I’m going to love both the same way.
2. I *wouldn’t care* disability or not/. They are still *my children*.

**Toni**: yes

**Stanza 64**: working out uncertainty

1. **John**: because *we want to see* how Maddie is going to be in a couple of years/. We don’t want to rush into having another *baby*
2. if Maddie is going to get *worse*/ cause if she gets worse both N and I have agreed/ we will only have *one child*.
3. But, if she gets a little bit better, we will think about having another child.
4. But then *there is* the 50/50 chance it could have the same as Maddie
5. or (.) because apparently skips a generation/ I’ve been told or/ (.) I think I might have read it.

**Toni**: [it’s statistics]

1. **John**: my sister doesn’t have anything like this/. I’ve got it/. It was me, then, my sister so it skips/ or (.) I think if Maddie’s got it/ if we have another child he might not/ but, then, on the other hand they might
2. and we both have said *we don’t care* but we will *deal with it* when it comes to it/.
3. **Toni**: yes… that’s… yes… parenthood is

**John**: yeah

**Toni**: yes, we give so much of ourselves.

**John**: we do

**Stanza 65**: interview ending

1. **Toni**: yes. Thank you so much for *talking with me,* really.
2. It’s been really (.) really good for me to hear your experience/ and it is going to be very helpful (.) to everyone.

**John**: ye

1. **Toni**: Thank you. So I’ll stop this.

**Appendix 6: Kate’s transcript micro and macroanalysis**

**Part 1: reaching out to practitioners and not being taken seriously. Was it because of lockdown?**

**Strophe 1: struggle during lockdown**

**Stanza 1:** introductory question about interaction with practitioners.

1. **Toni:** It is recording now, I believe. So, that's good. Yes. Yes, it is.
2. Okay, wonderful. So Thank you very much Kate again for meeting with me to talk about your experiences of your interactions with practitioners. So, that is really what I would like you to tell me about ah
3. (1) what have your interactions with practitioners been like?/ You don't need to go in any order/. You can just tell me about what comes to your mind as most relevant.
4. And practitioners could be *nursery nurses,* if your little boy goes to school or nursery/, or it could be *doctors*/, it could be *health visitors*/ *psychologist/ speech and language* *therapists/*, the people from *FA*/. So, anybody really, who has given you advice on your son or assessed him/. Okay. So, yes.

**Stanza 2:** things not being picked up due to lock down

1. **Kate:** so I first contacted a speech and language therapist when Lee was/ (.) he was close to two/, not said *anything at all*/ (.) I decided to try and *reach out* to somebody
2. (.) we did struggle a little bit with him been born in the middle of Covid that
3. (.) we didn't get that support from the health visitors/, as we probably would've done at a different time.
4. It was just/ (.) because of the time he was born/, I think/ (.) obviously it was *in the middle of lockdown* and
5. so (.) we did feel that we missed out a little bit there and, maybe, ah, things that would have been picked up earlier (.) *weren't*

**Strophe 2: reaching out to the speech and language therapist**

**Stanza 3:** checking what is ‘normal’ development

1. (.) he's my only child so I've got *nothing* to compare it to really./ So it was only really looking on Google and seeing what sort of milestones should be hit when
2. (1) that I thought I need to sort of contact somebody and see if I can get any help (.)
3. And so I reached out to the speech and language therapist/, who was *absolutely great*.

**Stanza 4:** help from SALT

1. He came and arranged a home appointment with us.
2. So he came around and spent about an hour with Lee.
3. Gave us some tips and things that we could try.
4. We also got referred to a paediatrician after that visit/ (.) I went to see the paediatrician/ who and again (.) was great

**Toni**: [Yeah]

**Stanza 5:** starting nursery

1. at the time Lee wasn't in nursery/. So he encouraged us to
2. (.) were kind of thinking about starting him a couple of mornings a week in nursery anyway
3. and he said that it could be helpful if we could do that.
4. So we did/ we started in two mornings a week in nursery
5. nursery have been absolutely brilliant (.) with him

**Strophe 3**: pushing and waiting

**Stanza 6**: having to push all the time

1. ah (1) We've *just found* that/ (.) There's been a *huge* delay/ (.) from getting the next appointment
2. (.) So I've/ I just feel like I'm having to push *all the time* to try
3. (.) and it's not really in my nature to be that pushy, but I'm just thinking if I don't/ (.) *nobody will* and…

**Toni:** Yea

1. **Kate**: I'm having to ring up/ and chase things all the time to get that *follow up* appointment/

**Stanza 7**: Assessing for autism a lengthy process

1. ah (.) we did manage to get a follow up appointment with the speech and language therapist/ (.)
2. and they started the process to assess Lee for autism.

**Toni**: right

1. **Kate**: And they did say it was quite a lengthy process.
2. There would be numerous people that would need to give their opinion on (.) on it/ because it's not just a case of being able to do a test which tells you

**Toni**: [No, there are different professionals involved.]

**Strophe 4:** help is good when we get to see practitioners

**Stanza 8**: moving things forward

1. **Kate**: Yeah/. So we then filled forms/, and we've sent one to nursery for them to fill in some forms./ And speak and language have now done that
2. We have now got a letter from/ (.) after me, calling and battering them/ we have now had a follow-up letter for the paediatrician in August/
3. so we are due to see him again in August/ when I think kind of a decision might be made on that.

**Toni**: Right. It's very close now.

**Stanza 9**: helpful support

1. **Kate**: yea, we’ve found that when we do get to see people/, they've been really great/ (.) they’ve given us lots of tips and things.
2. We have also been on a course, which was LC. And that was through A for C I think/. It was the same people that organise

**Toni:** [FA? FA].

1. **Kate**: That's right/. So that was good/. That was a six-week course that we attended.

**Strophe 5**: Who is the health visitor?

**Stanza 10**: health visitors had not been involved

1. I have found/ and I don't know whether it is because of Lee being born in lockdown/ and not having that/, ah (.) a health visit
2. (.) I mean, It was going to start the Lee that we/ (1) kind of knew that (.) he should have been speaking and *he wasn't*
3. and they've given us *tips* and things.
4. But *at that point*/ they said/ who's your health visitor/ (.) and I didn't *honestly know* who they were (.) so
5. **Toni**: So, you didn't see the health visitor at all?
6. **Kate**: *No* we didn't

**Stanza 11**: finding Lee’s health visitor

1. and it bizarrely enough, our health visitor was sat in the same room and did say to us
2. (.) cause she had a little girl with a similar time
3. (.) and she said: “I’ll look into it. I’ll find out who your health visitor is”
4. We then got a call to say/, I'm really sorry/, it’s me.

**Toni**: Right.

**Strophe 6:** interaction with the health professionals

**Stanza 12**: there wasn’t a relationship

1. **Kate:** We didn't know each other.
2. We didn't have that relationship which
3. (.) I think a lot of it was down to Covid

**Strophe 6**: check-ups did not show anything

**Stanza 13**: interactions on the phone

1. (.) we did have a couple of telephone calls/ (.) from different people/ (.) early on.
2. They kind of discharge us quite quickly when there was not
3. (1) He suffered with colic and things like that/ (.) there was no real/ (.) everything was fine with check-ups and everything so they didn't have (1)
4. **Toni**: Physically everything was Okay.

**Kate**: Yeah

**Strophe 7**: check-ups did not show anything

**Stanza 14**: health visitor’s visit

1. **Toni**: What about the health visitor?/ So you met her at little learners/ then it turns out that is your health visitor and

**Kate**: Yeah. Yeah.

**Toni**: then did she have a role to play in the long term or was it just…?

1. **Kate**: Ah, she then arranged an appointment to come round/(.) I think when Lee/ (.) it was his two year appointment
2. (.)where she was just kind of saying: “can he do this? Can he do that?”/ and “where's he at with things?”

**Stanza 15**: getting help from health professionals

1. ah (.) obviously with the speech and things she did say that there was a speech delay
2. (.) but she didn't really have any (.)
3. she did refer us for an appointment to get his hearing checked. We went for a couple of those/ and they said, everything was absolutely fine with his hearing.
4. ehm (.) But I have felt like/, really/, it's been on me really to *push* for further appointments, ehm

**Stanza 16**: summary of Kate’s narrative

1. **Toni**: So for you, the concern was the speech (.) and was there anything else or/ would it have been better if/ I mean (.) I think what you are telling me is/ (.) You would have felt/ (.) better served by practitioners being able to, to/ (.) say, ok so/ (.) or to be more involved in the first two years
2. maybe because of Covid, maybe because the health visitor wasn't visiting at the time/ (.) there was a gap there
3. (.) you felt that there was something amiss/ (.) there was something that there needed to be looked at
4. but it was you who had to look for it.

**Strophe 8**: not been listened to by practitioners

**Stanza 17**: concerns were dismissed

1. **Kate**: Yeah/, I mean even with the colic and things/, I mean/, they were saying/ (.) you get a *fussy baby*/ and *(.) in my opinion*/ it wasn't that.
2. He wasn't feeding normally.
3. He was really struggling/. He struggled with sort of his tummy and things like that.
4. I just felt because nobody was actually seeing him
5. we kind of just put it down to / (.) babies can be a little bit fussy

**Stanza 18**: I was not taken seriously

1. Ah (.) maybe that's it/ (.) but as I said, Lee is my only child/ so I've got nothing to compare him to
2. but *in my opinion* (.) it wasn't.
3. And also/ *my mum*/ said to me/ it wasn't normal.
4. But yeah/ when I was saying that/ I didn't really feel like I was being taken particularly seriously.

**Stanza 19**: lack of advice on concerns about speech

1. And even with the speech/ it seemed to take a long time before
2. (.) like they were saying every child is different/ and I appreciate that/ (.) and it's not that I'm thinking you need to hit these milestones/ but *I knew* myself there should’ve have *been*

**Toni**: Yeah.

1. **Kate:** even if there weren’t many words/ (.) there should’ve been something/. I mean, he's three now and he's not said a single word
2. and it seems like/ (.) it's taken a long time for them to really take me seriously

**Strophe 9**: identifying justified worries

**Stanza 20**: finding out if people are worrying unnecessarily

1. **Toni**: and you are the mom/ you know him the best and/ (.)you need to be listened to
2. **Kate:** and It’s also hard because/ (.) I mean/ (.) you hear it *all the time/* and you do get some people that maybe/ (2) push for things that/ that are not there/ and *I get it*.
3. And that's why/ I think it's so hard over the phone to kind of know/, whether somebody's maybe, maybe/ (.) just being a little bit/ ah (.) *worrying unnecessarily*/ or whether there is something
4. and I just felt like/ (.) I would have felt *better* myself if somebody would have said*: bring him in/*. Let's look at him.

**Stanza 21**: advice from SALT

1. And it was only that appointment that I arranged with this speech and language therapist/ where he said/: look, I will come around/. I will arrange to come around
2. when he said, yeah, he should be talking.
3. We can try this, we can try that

**Strophe 10**: we followed advice but we were not taken seriously

**Stanza 22**: interactions with Lee were already happening

1. And we've tried to put all these things in place and
2. I just think/ (.)/ we talk with him all the time/ we do all things that they said to do/ and
3. (.) as I said/ he is our *only one* so he gets our full attention/ there's/ he's the only baby in the house.
4. So Yeah, I do feel like we're talking to him all the time

**Stanza 23**: concerns were not taken seriously perhaps due to Covid

1. and (.) there was no eye contact./ He wasn't responding to his name and
2. (.) I just didn't *really feel* like I was being taken seriously initially.

**Toni:** Yes.

1. **Kate**: that could be down to Covid/ and not being able to have those home visits at the time.

**Strophe** **11**: evaluation of Kate’s experience

**Stanza 24**: Toni highlights Kate’s experience needs to be heard

1. **Toni**: I think it’s really relevant what the/ (.) your experience
2. and I don't think it's only you/. I think there are other people that have had similar experiences
3. so it needs to be highlighted/ and it is something very relevant to this/ to what I'm doing/ to tell the practitioners/. So this could be done in a different way.

**Stanza 25**: evaluating interactions with practitioners

1. **Kate**: Yeah, the last thing I want to do is to/ (.) to sort of slit the NHS because we are so lucky to have it.

**Toni**: *Yes*.

1. **Kate**: And people that we have seen have been *absolutely brilliant/*. When we've managed to get that appointment/ they’ve been great
2. but it's just getting that appointment.

**Part 2: support implemented and how it has worked**

**Strophe 12:** seeking support from practitioners

**Stanza 25**: contacting SALT

1. **Toni**: How did you contact the speech and language therapist?/ I'm just curious.
2. **Kate**: I actually found a post on Facebook.
3. I was scrolling through to find something in Cumbria for a speech and language/ and I just came across a poster/ that said that you could contact them on a Thursday between the one and three.

**Toni**: [right.]

1. **Kate**: And I contacted them.

**Stanza 26**: contacting I Can

1. And I also contacted another/ (.) have you heard of “I Can”.
2. **Toni**: I Can is a national institution, isn't it?/ Like a charity
3. **Kate**: Yeah/ I contacted them as well and they were *brilliant*/. I had a few phone calls with them/ (.) and they were great
4. but just felt like I needed something more local/ that would kind of help

**Strophe 13**: taking Lee to nursery was the right decision

**Stanza 27**: he was getting what he needed at home

1. and he said, as well, about nursery
2. (.) he did say that you do find that if they are in nursery/ they do push for additional help for you
3. Because I didn't need to send him to nursery/. So I didn't.
4. (.) because I thought/ (.) he doesn't/ (.) everything he's getting/ he's getting at home.

**Stanza 28**: but he was missing out on interacting with children

1. But it was that interaction with the children that he was missing out on.
2. And I totally get it when they were saying it might be good for him to go.
3. So we did send him two mornings a week
4. **Toni**: Did you do it because of the speech language and language therapist advice?
5. **Kate**: Yeah, they did say that they pick up a lot of the children/ and you may find that when he starts *nursery*/ (.) he comes on a lot/.

**Stanza 29**: his speech has not improved but he loves it

1. And he has been there now since/ he's done a full year at nursery
2. and there's been no change in his speech.
3. Oh, ye, socialising/ it does seem to have come on
4. and (.) I am glad that we did send him to nursery/ because he struggled at first/ but now he loves it/ he loves going

**Toni**: That's great.

**Strophe 14**: nursery staff are requesting extra support, it is not just Kate

**Stanza 30**: we have started the process of getting extra help in school

1. **Kate**: And his teachers have been *brilliant*/. They're putting things in place/ and (.) the additional help that we've signed forms and things for them to apply for.
2. So, I'm hoping that because we got him a year ago/ (.) and we're well on our way to getting the additional help.
3. Whereas if you haven't started until September/ would be a year behind.
4. So I am glad that we've done it

**Stanza 31**: nursery is pushing in the family’s behalf

1. although it hasn't really helped with the speech like we would’ve hoped/ but it's helped in other ways that we couldn't have foreseen.

**Toni**: Yes.

1. **Kate:** I'm glad that we have done it
2. and I do feel that /(.) by having them pushing on our behalf as well/ (.) it's not just me saying there, there's something

**Toni**: [It’s the school]

1. **Kate**: It’s not an independent person saying/ I think he does need that bit of extra help/ so I am grateful to them for that.

**Strophe 15:** emotional support is provided by Kete’s family

**Stanza 32**: Is there enough emotional support?

1. **Toni**: Wonderful. So once you got/ (1) the help from the practitioners/, it seems that your experience has been positive.
2. So nursery has been (1) a good experience because of the help getting this extra support for Lee/ and because he's been able to interact with all the other children.
3. Is there/ (.) what about emotional support from nursery/ or from other practitioners for parents/ for you?/ Is there enough emotional support?
4. I mean/, you also go to M groups?/ Is there anybody/ or any…/ (.) Is there enough help for the parents/ emotionally?

**Stanza 33**: unaware of services providing emotional support

1. **Kate:** I think that the most sort of help to me has been the M/ (.) they've been *really good*./ (.) maybe there are more things.
2. It's maybe a bit unfair for me to say/ because I've got a really good family/ and I've got a good support network/ that I haven't really needed that support from them.
3. So, maybe I haven't really looked for it/ if that makes
4. (.) I wouldn't want to say it's not there/ because it's not something that I've Kind of tried to seek out/. And I do feel like

**Part 3: what would be different if Lee is diagnosed with autism**

**Strophe 16: autism is unknown to Kate**

**Stanza 34**: feelings and knowledge on autism

1. **Toni**: Right. So you haven't needed it.
2. **Kate**: *No, no*/ I mean I do feel/ (.) A little bit/ (.) when they mentioned the autism and things.
3. And I did mention this morning/ when I went/ (.) that, I didn't know anything about it/. I don't know anybody who's autistic
4. and I think that/ at the minute we are a little bit in limbo because he hasn't had that diagnosis

**Toni**: [Yes.]

**Stanza 35**: parenting different with a diagnosis

1. and maybe when he does get it/ if he gets it/ ah (.) then it'd be helpful for me to be able to know how to parent him differently
2. because it’s hard when you can't communicate.
3. It's hard when (.) you're not able to say don't do that/ or don't run on the road/. It’s hard because I’m having to

**Strophe 17:** emotional and practical support needed around autism diagnosis

**Stanza 36**: Kate knows Lee and wants to learn about autism

1. **Toni:** [I]/ Lee will be Lee/ with diagnosis or without diagnosis, *won't he*?/

**Kate**: [Yeah.]

1. **Toni**: So (.)/ and you know him well so you might know better than anybody else what works/ what doesn't work.

**Stanza 37**: Kate needs support

1. But *yes/*, I believe there are courses/, EB and courses.
2. That if he gets the diagnosis/ you'll be able to access.
3. So obviously/ what you are saying (.) makes a lot of sense/, doesn't it?
4. That you want to know more about autism/ (.) if your son has autism/ (.) you want to know everything that is available to you/ so that's /(.) understandable.

**Strophe 18**: reasons to seek practitioners support

**Stanza 38**: pushing to get early intervention

1. **Kate**: and everything you *read*. It kind of says that early intervention is so important/ for a good outcome/ that I'm thinking
2. this is why I'm really pushing
3. because I think he's only three/ (.) if there's anything I can be doing that will help him/ I want to be doing it

**Stanza 39**: what do I need to do differently?

1. and as I said/ ah (.) It’d be useful for me to know what I need to do differently/ because it's not something I’ve ever had to (.) I’ve experienced before.
2. So it would be good to know (.) what to do
3. so I'm thinking/ (.) maybe/ if he does get that diagnosis/ I will then be seeking out additional help/ because it's (.) quite alien to me
4. as I say, I just don't know

**Strophe 19**: gaining help to navigate interactions outside the home

**Stanza 40**: meeting the needs of a perfect boy

1. And he’s great/ and he's happy and to us he is *perfect*

**Toni**: [Yes].

1. our perfect little boy/ and I think/ (.) But I'm more kind of thinking as he gets older/ it's gonna become harder if he can't communicate/. It's more for his *needs*, really, I'm thinking
2. (.) if we can/ sort of build all other ways of communication for him when he's not home/ when he is in nursery and things like

**Stanza 41**: how is he going to communicate?

1. We've started potty training/ and I think/ at the minute he's okay because he's at home/ but if he goes to nursery/ how is he gonna tell them that he needs the toilet?
2. Just little things like that/, I'm worried about that.
3. if anybody can help me/ (.) in how to deal with these things/. I’d find it really useful.
4. **Toni**: Yes, definitely. So there's /(.) yea the good communication between nursery and home/. So this again, been listened to isn't it?

**Kate**: Yea

**Part 4**: finding containment and the importance of having someone “fighting your corner”

**Strophe 20:** frustrations and hopes around appointments

**Stanza 42**: Kate’s partner also gets frustrated about waiting

1. **Toni**: So just another question/. I don't know if you have a partner.
2. Does he have the same thoughts about Lee/ and how practitioners have helped out?/ Or do you think that he's on a different page/ to where you are at the moment?
3. **Kate**: No. I think that we are kind of on the same page.
4. He gets frustrated at times/ that things are taking so long to get to that next step
5. (.) because like me/ you would just want the best for Lee/ and we find it frustrating when nothing's happening

**Stanza 43**: hopes about appointments

1. Even just having this appointment that we're going to next month has given us a big lift
2. because we think we've got something there

**Toni**: Yeah.

1. **Kate**: We’re going to this appointment and *maybe* something will happen there.

**Strophe 21**: Kate pushes because Lee is her priority

**Stanza 44**: then nothing happens

1. But sometimes you do feel a little bit in limbo
2. you've had your appointment and everything went *great*
3. ah (.) then/ like we had the appointment with speech and language/ and they said this is what we're going to do next
4. and then you don't hear anything for weeks and weeks and I'm thinking

**Stanza 44**: feeling selfish and frustrated about chasing practitioners

1. some of it was just a case of/ ‘I'll send you an email with this’/. I'm still waiting for the email
2. and I'm emailing saying/ ‘I haven't had anything following our telephone conversation’ and I'm just thinking/ that's the most frustrating thing
3. and I know that everybody you talked to/ just says they’re absolutely snowed under/ and I get that/. I totally do.
4. But from a selfish point of view Lee is my priority

**Stanza 45**: I want the best for him

1. **Toni**: No, it's not/ obviously/ and it's not selfish at all/ it’s a
2. **Kate**: and as I say, it's not really in my nature to be that pushy
3. But (.) because he is my everything./ I want the best for him/ ah (.) so, yeah/ I am onto them all the time.
4. I am pushing for that follow-up appointment/ because I just think it's important that we get that help.

**Strophe 22**: what needs to happen for practice to improve

**Stanza 46**: how could things be better?

1. **Toni**: Yes, of course it is (.) Yes
2. So (.) just about how/ (.) I think you have already given me a good idea/ but for the future/, how could things be better?/ What future do you expect for Lee?/ How would you like things to be?
3. And, if we can think about practitioners also/ (.) how could they do better?/ what do you expect from them?/ How can they attend to your needs the best way they can?

**Stanza 47**: having someone fighting your corner

1. **Kate**: I think really it's just on the length of time of waiting between appointments/ I think if that could be cut down/, it would be helpful to everybody.
2. Because it is a worry/, isn’t it?/ You just want the best for your children and
3. (.) I think just having that appointment and knowing that there's somebody there/ that's fighting in your corner it's priceless/, really.
4. And (.) yeah, I just find that the wait between the appointments is the most frustrating thing.

**Stanza 48**: practitioner’s role to reassure parents

1. **Toni**: I wonder Yeah (.) If/ (.) obviously everybody is very busy/, the paediatricians/, the speech and language therapist/. Everybody is very busy.
2. I wonder if having someone, maybe someone impartial, a different service who can just reassure/ (.) who can reassure the parents would be helpful/,
3. eh (.) maybe that could be something that helps, so, going forward.

[Toni’s phone rings for a moment]. Sorry about that.

**Strophe 23**: requesting support

**Stanza 49**: support during EHC needs assessment

1. So you have the appointment with the paediatricians/ and school has already asked for extra support for Lee or (.)
2. **Kate**: Yes, eh (.) they've applied for it.
3. So, I signed a form a few weeks ago/ and said that I was happy for them to go ahead and apply for it
4. They did say that it will take a while/. I think somebody needs to come in and do an assessment at nursery/, which I'm guessing now is going to be after September.
5. And then, we're hoping that/ it might be in place for when he starts properly in the following year/. If not before

**Stanza 50**: emotional support from nursery

1. **Toni**: So you have had enough support so far for it/ and you think that there is enough help from nursery, or
2. **Kate**: Yeah, as I said/ (.) I mean I am very fortunate I've got a good support network around me/. I don't know what it would be from/ (.) maybe a different perspective.
3. If people haven't got that support for them/, I don't know how they would feel or
4. But as I said/, it's not something/ I've actively sought out/ so I wouldn't want to say it's not there/ (.) because there might be more support

**Stanza 51**: improve communication with practitioners

1. **Toni**: Yes/. And from a practical point of view also/, the EHCP takes time and there are different people that will assess a Lee/ (.) So you feel you know what’s going to happen and nursery has been quite proactive in getting the help.
2. **Kate**: Yeah. Yeah/, they have
3. but like you mentioned before something like that/, where you could maybe have/ (.) not necessarily the professional
4. but just somebody there to give you a call and say *‘How's everything going* on?/ This is where you are In the list/ and this is what we're planning on doing next’.
5. And I think that would be really*, really* useful.

**Strophe 24**: benefits of attending groups with other parents of children with SEND

**Stanza 52**: How did it feel attending the groups?

1. **Toni**: Yes, and you told me that Lee is your only child/ you haven't dealt with special needs before.
2. So what about, eh… (1) the groups you go with F A (1)/ where you can meet other parents/ or even the LC/, that runs over different weeks with other parents/ (1) tell me more about it/. (.)/ How did it feel going to those groups?

**Stanza 53**: reassurance from sharing experiences related to SEND

1. **Kate**: They've been really good/. Yes/, they've been really, really useful and
2. like I said/ just to see other parents in the same position
3. and hearing about things that have worked
4. and even (.) maybe older children/ my child wasn’t talking at three but now they have started/ that gives you a little bit of support that/, ah (.) Yeah, they were late

**Toni**: [Yeah, it can change].

**Stanza 54**: reassurance from sharing general parenting experiences

1. **Kate**: yeah, and also with little things/. Maybe not even connected to the speech,
2. but things like (.) Lee has never been a good sleeper/ and you hear things where people are saying my child sleeps all night through/ and it's nice to/ *maybe* go to these groups/ where they're saying/: *No*, I've been up *for 4* as well/, so you're not on your ow/n (laughing)

**Toni**: Yes.

1. and it's quite nice to be around children/ that similar in nature to Lee
2. and just know that/ (.) you're not the only one that's/ been watching Peppa Pig from six o'clock in the morning and yeah (.) Yeah (laughing).
3. **Toni**: Yes, you are not alone.

**Strophe 25**: Ending the interview.

1. Yes, So yeah, That's/ (.) That makes a lot of sense/. Is there anything that I haven't asked/ and you would like to tell me about?/ Anything?
2. **Kate**: No, I don't think so/, eh (2) No. it's (.)
3. I think you’ve been really good. Your questions have been
4. **Toni**: [thank you].
5. **Kate**: Yeah, no/. You really have/,it's been lovely to talk to you/. Yea/, I think I've given you a good overview of things.
6. **Toni**: *Wonderful*/, thank you very much Kate/. I'm going to stop recording that is Stop.
7. **Kate**: Absolutely.

**Appendix 7. David’s transcript microanalysis and macroanalysis**

**Part 1: Introduction. Practitioners who have been in contact with Rob and his family**

**Strophe 1:** so far everything’s been very good with Rob

**Stanza 1:** introductory question about interactions with practitioners.

1. **Toni**: I think we have started recording now.
2. Thank you very much David for coming to this interview with me

**David**: [that’s all right]

1. **Toni**: what I would like to talk about (.) I would like you to tell me about your interactions with practitioners you have seen regarding Rob
2. (.) so (.) it could be in any order.
3. If you can give me a little bit of background; what Rob is like, who has seen him, but it does not have to be (.) just, whatever experiences, whatever interactions (.) are highlighted in your memory (.) it is fine.
4. **David:** yea, so doctor, ah… speech therapist

**Toni**: [exactly]

**David**: and

**Toni**: nursery nurses in school. If you have seen the other day (.)

**David**: paediatrician, that’s the one I was trying to think of

**Toni**: yes

**Stanza 2:** He does not want to talk but everything else is fine

1. **David**: so far everything’s been very good with Rob
2. even though it’s been *a bit* difficult because (.) with him *not wanting* to talk/. You know, *he knows* words/ he just *doesn’t want to talk*.
3. They picked up on it at his nursery, C./ The teachers there said he seems to be a bit behind with his speaking
4. but everything else was fine.

**Strophe 2:** visits to practitioners

**Stanza 3:** referral to the speech and language therapist

1. and they said we could (.) send you to the speech people/ check his hearing and that.
2. So, they went through all of that for us
3. which was really great/ cause there is so many forms and so many different departments

**Toni:** [so they helped]

1. **David:** yea, you get a bit lost/ so they helped us doing that, ah.

**Stanza 4:** visit to the hearing specialist

1. And then we went to see the hearing specialist to see if Rob’s hearing was ok because
2. (.) obviously they have to check that/ because if he has a problem with his hearing/ his not going to pick speech properly, is he?

**Toni:** no

1. **David**: So we went to see them/ and they said that his hearing was fine.
2. He enjoyed that/ cause there was lots of toys and

**Toni:** (quiet laugh)

**Stanza 5:** visit to the paediatrician

1. **David**: and then after that we went to see the paediatrician

**Toni:** yea

1. **David**: which when he looked at him said it looks like he has hypermobility.

**Toni:** ok, with the joints

**David**: yea, with the joints

1. (.) he’s bendy and flexi/ and the way he sits down and that.
2. So that’s why he advised to keep him in high top shoes/ with the ankle support for him
3. so it was fine/ so, yea.

**Stanza 6**: conclusion: it has been good.

1. We have not had any bad things about them.
2. The nursery teachers all have been great with him.
3. I don’t have anything bad to say about C, to be fair.

**Strophe 3**: speech, language and communication needs

**Stanza 7**: Rob’s parents noticed he was not talking

1. **Toni**: you said, you did not really notice anything, eh, amiss
2. **David**: Apart from his talking.
3. We were wondering why it was taking to talk so long
4. because his older brother started talking and having conversations at around two

**Toni**: right

**Stanza 8**: ways in which Rob communicates

1. **David**: Rob is three now/ and he’s still not making sentences.
2. He will say the odd word now and again
3. but not thinking (.) a sentence to make you understand what he wants.
4. He’s just pulling and pointing.

**Stanza 9:** confirming a suspicion

1. **Toni:** going to nursery/, was it helpful for you to confirm your suspicion that (.)
2. **David:** yea, we thought it was taking him a bit long to talk
3. and then when they said: ‘he seems to be a little bit behind in his speak’
4. we were like ‘yea, we’ve noticed that.’

**Part 2: attending groups for children with SEND**

**Strophe 4:** attending speech and language groups

**Stanza 10:** arranging to attend the groups

1. So then they mentioned that there is the speech therapy specialist groups that you can go to and that
2. and that’s why they sent us to that one at H.
3. **Toni** : Yes, so are all the clubs you have been to or have you (.)
4. **David:** no they are the only ones

**Stanza 11**: knowing what to do

1. **Toni:** And how did you find them?
2. **David:** it was all right actually

**Toni: [**you can be honest]

1. **David**: most of the stuff they said to do we already were doing with him and that

**Toni**: yes

1. **David:** because having Sam we knew./ We looked at it all when Sam was born/, so I already knew all that.

**Toni:** right

1. **David**: so, the Internet is a great place to find things.

**Stanza 12**: other advantages of attending the groups

1. **Toni**: so, did you (1) gain anything else from the groups/ apart from just the advice/ (.) anything else? (.)
2. **David**: eh (.) not really, no/ because (.) we didn’t need much else, to be fair/, apart from
3. (.) Rob enjoyed it/, which is the main thing for me

**Strophe 5**: effects of Covid

**Stanza 13**: lack of interactions due to the Covid pandemic

1. cause of Covid and that/ (.) and he had been locked in the house/ he hadn’t had much interaction with anyone until he went to nursery.
2. Now, he’s started to see more people/ and be out more.
3. **Toni:** yes. So when he was referred to the speech and language therapist by nursery, was this after Covid?
4. **David**: ah, this was just about the end of Covid, yea

**Toni**: the end of Covid

1. **David**: It took a while to come through and that's so, yes.

**Stanza 14**: getting help during the Covid pandemic

1. **Toni:** So would have you looked for the advice of practitioners before/ if it wasn’t Covid?/ (.) did it change anything/ or not at all?
2. **David**: eh, yea Covid probably changed/ (.) yea, because we probably would of/ (.) if there wasn’t any Covid/

**Toni:** yea

1. **David**: we probably would have looked at getting some help sooner/ but with Covid going on and that

**Toni**: yes, it was (.)

1. **David**: It was just like trying to (??) of people as much as possible, so.

**Strophe 6**: expanding on the groups David has attended with Rob

**Stanza 15**: advice from speech and language therapist

1. **Toni**: so, the speech and therapist, was it helpful advice?
2. **David**: I already knew most of it.
3. There was a couple of things
4. (.) we’ll try that but most of it we already knew.

**Stanza 16**: groups for children with SEND

1. **Toni**: yes. You also go to the M groups, don’t you? The other day (.)

**David**: oh, the soft play ones?

**Toni**: yes

1. **David**: he’s been there a couple of times beforehand/, before the groups were on.
2. I just took him/ and paid to go in.
3. He’d enjoyed that.

**Strophe 7:** finding out about places to go with children

**Stanza** **17**: information from the groups for children with SEND

1. **Toni**: How do you find them?

**David**: How do we find that one? As in, how are they?

**Toni**: yes

1. **David**: *hhe* enjoyed it./ It was good, not bad.
2. They gave us some information about things that were going on/. It was something to do with a farm,/ it’s at the end of P road,/ which we did not know about.
3. **Toni**: so practical help

**Stanza 18**: exchange of information as belonging to the group

1. **David**: yea, well (.) people there knew information that we didn’t know.
2. If we had heard of something that was going on/, we would have said: ‘there is this one as well’.
3. So, there is no many places around/ where you could go and just do that/ cause normally you just (.)

**Strophe 8:** what makes the group better

**Stanza 19**: parents’ interactions

1. there is LS is in P road/ but everybody is always on their phones
2. and they just let the kids do what they want
3. while that seems to be more interactive.

**Toni**: right

1. **David**: more people talking to each other and that

**Toni**: yes

**Stanza 20**: common purpose

1. **David**: it seems to be better
2. **Toni**: So you seem to feel better there?
3. **David**: Yeah. I think because everyone is there for the same reason
4. whereas other places are just/ (.) yeah, I’ll just get rid of my kid for a while/. There you go.

**Strophe 9:** interactions between parents, children and with practitioners in the groups

**Stanza 21**: a good level of interaction

1. **Toni**: yea, so can you tell me a little bit more about that/, about interacting with other parents/. Is there enough interaction?/ Or should there be more?/ I don’t know, what are your views on that?
2. **David**: in that group it seems to be about right/. The kids were playing/. We go to check on them
3. and then people will have some information to say about things going on and that
4. but you also are left to do what you want with your kid as well.

**Stanza 22:** overwhelming parents with information

1. So it wasn’t like (?) in your face so (.) Sometimes it’s all a bit much.
2. They want to give you all this information/ and want to talk about this (.)
3. and you are like: ‘can you give me five minutes, please’ (quiet laugh)

**Toni**: yes

1. **David**: yes, but it was better than I expected it to be
2. because he’s been a couple of times/ but he’s nana’s took him/. That’s the first time we took him, you see.

**Toni**: right

**Stanza 23:** what was helpful in the groups

1. **David**: But yea, it was all right that/ cause there weren't too many people/ and the kids were all friendly and that/. There weren't too many people (.)
2. **Toni**: What about for the parents? What was helpful for you and Lynn?
3. **David**: eh, well, just helpful for us to let Rob run around/ and let off some steam
4. and to have fun (.) without hurting himself/ like he normally does.

**Part 3: Not being listened to**

**Strophe 10:** an specific problem

**Stanza 24:** playing with the water and getting wet

1. **Toni**: And is there anything that may have been less supportive/ or may be think: ‘this shouldn’t be like that, it could be done in a different way’ in the group you have been to/ or interactions with school/ (.) with C nursery/ or any other practitioners?
2. **David**: eh, in nursery he gets sent home a lot after school with a lot of wet clothes/ cause they let them play in water.

**Toni**: right

1. **David**: and it’s not to bad when it’s one change of clothes
2. but when he’s got 4 or 5 change of clothes in his bag/ and they are all soaking wet/ and then I am picking him up from nursery/ and he’s wet as well (.)

**Toni**: right

**Stanza 25:** getting colds as a result of being wet

1. **David**: it was near winter/ (.) when it was really bad/ he was coming back/ and he was freezing.
2. And he was getting colds and was ill all the time
3. and it was obviously because he was getting soaking wet and freezing cold so/ (.) that’s one thing that irritated us, that’s (1)

**Strophe 11:** David’s solution is ignored

**Stanza 26**: proposing a solution

1. **Toni**: Did you sort it out/, what happened next?
2. **David**: Well, I said they should turn off the tap or something like that.
3. They were like, there is no (cut off?) on it.

**Toni**: right

1. **David**: So I was like, well, it is easy to put a stop valve in a tap.

**Stanza 26:** the situation stays the same

1. **Toni**: Did anything change?
2. **David**: no, no, nothing changed (Toni and David laugh quietly).
3. He still came home wet but it is summer now/ so it’s not to/ (.)
4. I don’t mind it in the summer/. I let him play with as much water as he wants in the summer/. It dries out and it’s warm enough but in winter (.)
5. **Toni**: yes/. So that’s a very specific example for a practical thing that, yea./ It makes sense that/ if it is winter/ you might get cold/ maybe he shouldn’t be playing with the cold water.

**David**: [yea]

**Strophe 12:** nursery following their rules without knowing Rob. It does not work.

**Stanza 27:** attendance is ‘not up to the level they want it to be’

1. **Toni**: eh, is there anything else? you don’t feel listened to in other ways?

**David**: ehh

1. **Toni**: What is the relationship like with the nursery?
2. **David**: apart from that it’s very good actually/, apart from them (.)
3. Oh, there was one thing/. They said that his attendance wasn’t up to/ (.) wasn’t up to the level that they wanted it to be.

**Toni**: yes.

1. **David**: I said well you are sending him home all the time sick so (.)

**Toni**: ahhh

**Stanza 28**: in a ‘catch 22’

1. **David**: they phoned me up to say he’s not feeling well, yea
2. and it’s like he has to have 48 hours off/. Well, there is the time, the attendance’s gone.

**Toni**: yea

1. **David**: and then they are complaining to us.

**Toni**: [yea]

**David**: (.) it’s like, what?/ You sent him home./ Then, he’s got to have 2 days off.

1. We’ve never kept him off.

**Toni**: yea

1. **David**: it’s only when they send him off

**Stanza 29**: David’s response to the nursery staff’s phone call

1. and then they are complaining that/ (.)(quiet). It’s like ‘no, shut up’.
2. I don’t know what they expect us to do with that one/. Send him on a weekend to make up for it?
3. **Toni**: ye, (?). They weren’t aware of (.) well, the situation (quietly laughing).

**Part 4: consultations with practitioners**

**Strophe 12**: sorting the EHCP referral process

**Stanza 30**: Getting started with the EHCP referral

1. Ok, so, eh (.) was it the nursery who started the EHCP process assessing Rob’s needs/ or was it (.) a parental request.
2. **David**: yea, yea/ they said that there were certain people who could come and look at him.
3. So, yeah, they were the ones who started things.
4. We filled in some forms/ and then they arranged all at school for us.

**Stanza 31**: nursery staff made the process easy

1. **Toni**: How did you find that process?
2. **David**: That was really good actually./ It was really easy.
3. They just gave us some forms/ and they said: ‘this is the form for this/. Sign that/ and we’ll send it off for you’
4. and then this one/, and we read it/ and signed it/ and they said ‘we’ll do that one for you as well’.
5. So, it saved us trying to figure out where they were going/ and phoning to check up where they needed to be/ so that’s (.)

**Strophe 11:** communicating with practitioners involved in the EHCP process

**Stanza 32**: difficulties when communicating with people who do not know about a situation

1. **Toni:** So on that occasion they were paying attention/ and they ensured that everything was done.
2. **David**: Yeah. That was really helpful because/ (.) you know what is like with any government.

**Toni**: ye, the bureaucracy.

**David**: yea/. It takes forever.

1. I’ve phoned the council countless times/ and then (.) ‘oh, I don’t know, I don’t know’/. It’s like, ‘I phoned you three times now/. You don’t have a record?’
2. **Toni**: ok. So on this occasion the nursery did a good job.
3. **David**: yea, they did a good job for that

**Stanza 33**: talking with the educational psychologist

1. **Toni**: so, who have you seen regarding the EHC needs assessment/. You saw L, I think. How did you find that/. Was it easy?
2. **David**: It was really good actually.
3. She was really friendly/ and polite/ and nice to talk to (.) yea/. I couldn’t say anything bad about her.

**Toni**: good.

1. **David**: she had lots of information/ and she was great.

**Strophe 12:** appointment with paediatrician was surprisingly quick

**Stanza 34**: the appointment came through quickly

1. **Toni**: That’s great. Going to paediatricians, how was…?
2. **David**: the paediatrician wasn’t bad actually.
3. The appointment came through much quicker than what we thought it was going to be.

**Toni**: right

**Stanza 35**: receiving the appointment quickly was unexpected

1. **David**: We thought we were going to be waiting a while/ because there are only one or two paediatricians/ and God knows how many kids.
2. **Toni**: ye, and usually. There is a very long waiting list.
3. **David**: yea, that’s what we thought/ but it was like two and a half weeks when we got the letter through the door (.)
4. and we went ‘oh, ok’/. We expected it to be like six months.

**Toni**: right

**Strophe 13**: what happened during the paediatrician’s appointment

**Stanza 36**: what the paediatrician did

1. **David**: And, we sat there and he looked at Rob and watched him playing with some toys (.)
2. and he was like watching him moving around
3. and asked us some questions

**Stanza 37**: what the paediatrician found

1. and it was all fine
2. and he says/, well, it seems like he’s got hypermobility
3. and apart from that/, his hand- eye coordination is fine.
4. He’s inquisitive

**Stanza 38**: what the paediatrician thought about Rob’s speech

1. there’s not (1) anything wrong with him apart from that (1).
2. He said his speech will probably develop over time himself.
3. He said there are things you can do to help it come along a bit so (.)

**Strophe 14:** diagnosis of hypermobility

**Stanza 39**: David was surprised about the hypermobility

1. **Toni**: So is that what you were expecting to happen?
2. **David**: we were surprised with the hypermobility
3. because we, I didn’t know about that
4. and I looked at it later on after he said/ and I was like ‘oh’ so (1)
5. that’s why you go to see the specialist innit?/ cause they know things you don’t know

**Stanza 40**: what to do next about it

1. **Toni**: yes. So was he referred to someone else/, the occupational therapist for that/ or there is no need at the moment?
2. **David**: they said there is no need at the moment/. It’s just to keep an eye on.
3. They said it should be fine/. He said in most cases there is no issue with it at all.
4. It’s just one of those things.

**Strophe 15:** when interactions with practitioners have been negative

**Stanza 41**: practitioners can be arrogant

1. So, yea. The paediatrician was good, friendly/ which is always helpful
2. cause sometimes when they’re a bit (.) aggressive or arrogant or pompous
3. you don’t feel like talking to them.
4. You don’t want to give them information/ (.) you are just like ok/ he’s here/ he’s looked at him/ goodbye.

**Stanza 42**: a bad experience with the health visitor

1. **Toni:** have you been in that situation where you have thought…um… this person is a little bit pompous and… is not really getting me?
2. **David**: emm (1), yes/, it was when Rob was much younger/. It was *theee*… home visit nurse/, I can’t remember (.)

**Toni**: health visitor?

**David:** yea

**Toni**: ahh, the health visitors

1. **David:** yea, when he was small and that/ and they came round/ and said ‘that’s how you do this/ and this is how you do that’
2. (.) we had a kid/. We know how to change a nappy/. We know how breastfeeding works/. We have had one before/. He’s eight/. He’s still alive/ so we did a pretty good job.

**Toni:** right

**Strophe 16:**  what did not work during the visit

**Stanza 43**: what made the interaction a negative one

1. **David**: But yea/. It was a condescending tone.
2. They were saying something to us/ and we were like, ok, we get the idea.
3. And we’ve only seen them once as well/. That’s the other thing/. We were meant to see them more often/, we saw them once (.)

**Stanza 44**: summary of what happened during the visit

1. **Toni**: right. Did they pick up on any special needs, anything?
2. **David**: [no]/. They came in/, said ‘this is how you should be changing his bum’/ and ‘this is how he should be fed’/ and ‘he should be having a sleep schedule’.
3. We were like (.) we know this/ we had a kid
4. and then they were like ‘well, ok, there you go/. Bye’.

**Toni**: Oh dear.

1. **David:** They were there for 20 min and they weighed him.

**Toni**: right

**Strophe 16**: uncertainty on what would happen next

**Stanza 45**: there was no follow-up

1. **David**: That's it. We were like (.) ok (.)/ Will we see you again?/ Are you coming back?
2. We don’t know.
3. That was all, bye.
4. I think we were meant to see them at his one year appointment/ and then so long after or something like that.

**Stanza 46:** there should have been follow-up appointments

1. There is a set amount of appointments you meant
2. (.) they meant to come and check on him to make sure he’s growing properly and things like that.
3. We only saw her once.

**Toni**: [right]

**David**: so

**Strophe 17:** David asked the doctor to check Rob

**Stanza 47**: clarifying timings

1. **Toni:** Is that because they, they missed you/ or because you were attending the paediatrician’s appointments…?
2. **David**: no, no. This was before the paediatrician’s appointments/. This was when Rob was like six months old.

**Toni**: right, ok

**David**: so

1. **Toni**: they didn’t do the two years check or anything like that?
2. **David**: no.

**Stanza 48**: the doctor checked Rob instead of the health visitor

1. We ended up getting a doctor to do the weighing and stuff like when I took him.
2. He had a sore ear
3. so I said while he is here can you do his check-ups.

**Toni**: all right.

1. **David**: and then he booked him for his jabs.
2. **Toni**: ah, so everything was done.

**Strophe 18:** the doctor had no concerns at that time

**Stanza 49**: the appointment with the health visitor was not going to happen

1. **David:** Yeah. We did it at the doctor’s that time
2. so we just thought that it would be easier that way/ than waiting around for an appointment that’s *never* going to happen.
3. **Toni**: ye, I mean, if the doctor is able to do it (.)
4. **David:** ye, he was fine doing it.

**Stanza 50**: the doctor said everything was fine

1. Weighing and that/ and measuring him
2. and he said everything was fine.
3. He was growing/, he was going to be a tall bugger.
4. **Toni:** So is that when Rob was 2 years old?
5. **David**: no. It was when he was 1/, just after his first birthday I took him/. He had a sore ear.

**Strophe 19:** when concerns started

**Stanza 51:** Concerns were identified at nursery

1. **Toni**: At that time there weren't concerns from you or anything like that (.)/ or the paediatricians also?
2. **David:** no, nothing/. (.) Eh, it was only later on in nursery
3. when he started that we noticed he didn’t want to talk and that so (1)

**Toni**: right.

**Stanza 52:** but everybody has been nice to him

1. **David**: but he seems ok
2. and everyone is being nice to him now so
3. **Toni**: Yes, he’s gorgeous

**Part 5: emotional and practical support needed**

**Strophe 20:** what could have been better and what has worked

**Stanza 52**: lack of opportunities to interact with others during Covid

1. Ok, so is there anything that you would wish would have gone in a different way/ or would have been different.
2. **David**: eh (2) no that I can think of (.) Maybe (3) more time with other kids when he was younger might have helped him a little bit
3. but with Covid and everything being shut.
4. **Toni:** Yes, everybody was in that situation

**Stanza 21:** helpful practitioners

1. **David**: yea, help wise everybody has been very nice and helpful generally.
2. **Toni**: They sound very proactive also.
3. **David:** Yeah. I noticed that everyone is trying to/ (.) like I said before (.) ‘there is this going on, would you like to go for this?’/ or ‘there is this going on would you like to go for that?’
4. Which is really good

**Strophe 21:** groups happening at the same time

**Stanza 54**: cannot attend the groups

1. cause tried to fit certain things around your schedule/ (.) sometimes you just can’t
2. when there are a few things going on (.)/ then, I can’t go to that/ but I can go to that one cause they are not all on the same day.
3. We had that with Sam when he was younger/, there were four groups on/, all on the same day.
4. **Toni:** (quiet laugh) That’s not very useful!

**Stanza 55**: spread the groups out over the week

1. **David:** well, Lynn was at work/ and I was doing other stuff
2. and it was like, well/, we can’t take him.

**Toni**: yes

1. **David:** and then it’s like, well, I’m free tomorrow/. Nothing is happening tomorrow.
2. So having them spread out in different days mean that/ if people are busy Tuesday to Friday/, there might be something on Monday they can go to.

**Toni:** yea

1. **David:** which is helpful

**Strophe 22**: help available for parents

**Stanza 56**: David and Lynn are quite self-sufficient

1. **Toni**: so, what about the help for the parents also/. Do you think there is enough support for you and Lynn?
2. **David**: eh… well, we are quite self-sufficient generally so (1)
3. **Toni:** Is that your choice?/ Is that the way you are?
4. **David**: That's just the way I am/. If I can do it myself/, I will do it myself.

**Toni:** right

**Stanza 57**: I could get help if needed

1. **David:** so, I don’t like getting help from anyone/ if I don’t have to.
2. It’s just the way I am/. I have always been like that.
3. **Toni:** That's fair enough/. I suppose what I was asking is/, if you would like some help/, do you feel that it is there?
4. **David**: oh, yeah. I do feel like if I needed some kind of help for some reason/, I would be able to get some/, if I really had to.

**Toni**: right

**Strophe 23**: being able to have a couple of hours for themselves

**Stanza 57**: respite

1. **David:** so, yeah (1) The only thing I can think of to help wise would be looking after Rob for a couple of hours.
2. **Toni:** ah, a respite
3. **David**: but he is at nursery so (.)
4. He is probably not at nursery as much as we’d like

**Stanza 58**: nursery hours

1. **Toni**: [how often does he go?]
2. **David:** he goes two and a half days/. On Monday, Tuesday and half Wednesday/.
3. Those are the hours we get.

**Strophe 24**: paying for nursery hours was a waste because he could not attend

**Stanza 59**: paying for nothing was annoying

1. We were paying for the other half of Wednesday/ but with him being off sick all the time (.)/ we were paying for nothing/ and we had to pay for it even though he wasn't there.
2. That’s one of the things that annoyed us about it as well
3. (1) so we were like, we’ll just sack that half of the day.

**Stanza 60**: he could not go because he was ill after being wet

1. **Toni:** and being ill would be these colds he would have for being wet or (.)?

**David**: yea

**Toni**: little things that add up

1. **David**: so we were like we’ll just get rid of the half a day/ because half of the time he wasn’t there on the Wednesday
2. cause he would go on Tuesday/ and he would wake up on Wednesday morning all coughing and snorting and not feeling well
3. cause he had been cold the day before/ and had got wet so (.)

**Stanza 61**: changing the nursery hours due to financial costs

1. We paid for about two months’ worth of Wednesday he didn’t go to/ so it was like (.) oh, why are we wasting our money?/ It’s £15 a week.
2. **Toni:** Yeah, so if you don’t have to pay it, you don’t.
3. **David:** And that’s 15 quid just for the afternoon/ that’s about (.)/ it works out to about £5 an hour, something like that.

**Strophe 25**: clarifying when Rob will go to school

**Stanza 62**: next year he will attend nursery

1. **Toni:** So things are going to change quite a bit cause Rob is going to reception/. He will be starting reception in September?
2. **David**: I think so, yeah, but it’s still only for two and a half days.
3. **Toni:** ahh, so then it is not reception/. It’s not a proper school.
4. **David**: not till the year after.

**Toni**: ah, ok, sorry, sorry (quietly)

1. **David:** so this coming September is still two and a half days

**Stanza 63:** going to school with his brother

1. **Toni**: and it’s the year after/ (.) that’s when he will be full time/. He will be going to school/ and he will be going to the same school, C?
2. **David**: Yeah. He will be going to C.
3. His brother is there/ and it is just up the road from our house/ so it’s handy (?)

**Toni**: very good

1. **David**: yes. It saves me driving them in the morning.

**Part 6: Rob’s needs and strengths. Ways to promote Rob’s language skills and keep him safe**

**Strophe 26:** the main concern is that Rob does not speak

**Stanza 64:** David would like practitioners to be able to help Rob to speak

1. **Toni:** so, is there anything you might need from (.) any practitioners or (.)?
2. **David**: at the moment we are more concerned about Rob’s speaking and/ (.) see how that is going to develop
3. but (.) apart from that, no (.)/ It’s just his speaking really.
4. We want to try to see if we can get him to talk

**Toni**: yes

1. **David**: and whichever person helps to do that the most he’s going to be very happy

**Toni**: (quiet laugh)

**Stanza 65**: he gets frustrated by it

1. **David:** because we’ve tried getting him to speak sentences/. Tried him to say words/, like apple, to an apple (.)
2. but he just doesn’t seem to want to. We’ve tried all sorts
3. (.) and he gets frustrated as hell (.)
4. when we are trying him to speak and he is like (grunt)/ and he’s pointing, pulling and poking.

**Strophe 27**: it is difficult to understand Rob’s wants and needs

**Stanza 66**: thinking about what he wants

1. And then when you don’t know what he wants
2. and he gets all angry/ and he starts screaming
3. and you are like ‘I don’t know what you want/. You want this?’ ‘no’ ‘you want that?’ ‘no, no’.
4. We went halfway around the kitchen the other day/, trying to figure out what he wanted.

**Stanza** **67**: he communicates but sometimes he gets frustrated

1. **Toni:** So you seem to be doing everything the speech and language therapist said.
2. You are giving him choices/ and he is taking you to places/, so he is communicating without really talking but he can (.)
3. **David:** Yeah. He does show us what he wants most of the time/ but sometimes he gets frustrated himself.
4. You can see him getting frustrated with it

**Strophe 28**: an example to illustrate the problem

**Stanza 68**: Rob wants an sliced apple

1. (.) and then you are like ‘well, I don’t know where to (.)’ (quiet laugh) (1)
2. Like yesterday when he got back, he wanted an apple
3. but he didn’t want an apple./ He wanted an apple sliced up (1)
4. **Toni:** Ahh, so it was the way of giving him the apple.
5. **David:** Yeah. I picked the apple up and then he put it back down but then/, he picked the apple and gave it to me.

**Stanza 69**: David got there in the end

1. I was, ‘I don’t know what you want me to do with that’/ Yea, apple, and he was giving me
2. and then I was like, oh, wait there/ (1) I might have an idea.
3. Then I sliced it/ and he ate it.
4. That’s what you wanted!
5. But the point is how the hell was I supposed he wanted it sliced (1)

**Stanza 70**: Rob does not focus on using different means of communication

1. **Toni:** ahh, has the speech and language therapist talked about objects of reference. He’s very little at the moment (.)/ maybe using some sign language
2. **David**: We've tried that (.)
3. He doesn’t want to, no (.)/ He just wants to go, yea, I’m off. Bye, bye (2).
4. So it’s one of those things.

**Strophe 29:** David’s business to help Rob’s progress

**Stanza 71**: Rob’s progress

1. He will get there eventually.
2. He’s started to say a few more words lately/. He started saying dinosaur the other day/ (.) ‘to a dinosaur’ (2)

**Toni**: wow

1. **David**: and his letters and numbers are getting much clearer to understand now (1).
2. **Toni**: He can count. I’ve seen him. I remember him going up to ten.

**Stanza 72**: what he can do

1. **David**: and then down from ten
2. and he does the whole alphabet (.)/ and the ‘b’ and ‘p?’/ which were really difficult/ he’s started pronouncing it more now
3. so he’s getting there slowly (1)
4. (quietly: it’s one of those things)

**Stanza 73**: David is always busy

1. He was asleep when I came out.

**Toni:** ohhh

1. **David**: I had been playing with him all morning on purpose (?)
2. **Toni**: so you are busy
3. **David**: I’m always busy/ I never stop/. I don’t get a break./ No matter what I’m doing/ I never get a break

**Strophe 30:** benefits of spending more time in nursery

**Stanza 74**: more time in nursery would help David

1. **Toni:** so (1) is that something you would like help with then
2. Is there respite now that he only goes two and a half days to nursery?
3. Is that where you think there is a gap here that (.)?
4. **David**: yea, if (.) I think if he was at nursery a little bit longer/ it would give us a bit more time

**Stanza 75**: it would also help Rob

1. and it would be better for him as well.
2. I think with him interacting with other kids more/ and playing more.
3. The more he does that/ I think the better he’ll pick up on certain things and words (.).
4. And, he’ll see a correlation between them saying something and something happening/ (.) I think that’s one thing he’ll start noticing more (.). The more he sees it.

**Toni:** yes (2) um

**Stanza 76:** a win-win situation

1. **David**: and also it’ll give us more time to do stuff if he is at school longer/.
2. I still have half a house to build (.).
3. **Toni**: yes, so it could be positive for both/, parents and for him
4. so (.) a win-win situation.

**David**: yea

**Strophe 31**: evaluation of appointments with practitioners

**Stanza 77**: appointments and help received have been good

1. **Toni:** um (.) so ok (.) is there anything else that I haven’t asked that maybe you would like to add.
2. **David**: not that I can think of (1).
3. Appointments and the doctors have been fairly quick when we’ve needed them./ We’ve never had a problem with that (1)./ All the help he’s getting
4. **Toni:** [that’s really good]

**Stanza 78**: change of health centre

1. **David:** well, I have to admit (.)/ We used to go to A Health Centre/, which was behind the town hall/ and they were very good then
2. when they moved to A B/, we were thinking: ‘it will be very bad now because they’ve moved’
3. but no/, it stayed the same so (.)
4. and every time Rob had an issue/ we made an appointment/ they’ve got an appointment really quickly/ waiting 3 days at the most, most of the time
5. so (.) that’s been good.

**Strophe 32:** help received has been good but sometimes David is tired to listen because Rob does not care

**Stanza 79:** help received from practitioners has been mostly good

1. All the help he’s been getting with his talking
2. and all the people we have been seeing have been really friendly and helpful mostly.
3. I can’t think of anything bad with any of them really.

**Stanza 80:** feeling tired

1. **Toni:** you said mostly there? (quiet laugh)
2. **David:** mostly (1) sometimes I am just tired so then/ I just don’t want to know.
3. I am the one who stays up at night with him, you see.

**Toni:** right

1. **David**: when he doesn’t want to go to bed/, like a quarter to twelve last night/. That’s when he went to sleep last night
2. Then he woke up at bloody seven this morning.

**Toni**: ahh

**Stanza 81**: Rob does not care

1. **David:** I’m like: ‘what are you doing, you little monster’

**Toni:** (quiet laugh)

1. **David:** he doesn’t care (.)
2. He wanted breakfast and a cup of tea.

**Toni**: yea, that’s (.) *children*

1. **David**: He wanted what he wanted. I said ‘ok’

**Strophe 33:** evaluation of interactions with nursery staff

**Stanza 82**: one occasion in which school has not been good

1. but, yea, they have been good
2. School has been good apart from getting wet (.) in the winter/ (.) which is silly, really, I think.
3. In cold weather you don’t want to be soaking wet
4. and then when we were picking him up, he was still in wet clothing/. (quiet voice) It was like oh, Jesus Christ.

**Stanza 83**: apart from that exception school has been helpful and friendly

1. **Toni:** yes, you are giving me this example (.)/ so you are saying this is when they are not listening, really,
2. but otherwise you seem to be thinking (.)
3. **David:** ye, apart from that one little thing/, it’s been all right.
4. Like the reception staff have been really good/ and that they’ve been really helpful and friendly with him.
5. I think they are starting to know him a little bit better now.

**Strophe 34:** Rob does not stop but apart from the health visitor everybody has been good with him

**Stanza 84**: Rob never stops

1. Still a handful/. He doesn’t stop/. He is like the energising bunny.
2. **Toni:** Ahh, *yes*. I have seen him actually/ and, ye, (.) he’s into everything
3. **David:** [never stops going] he’s always into something/, specially if you don’t want him in it. Ye, if he is not allowed in there/ he’s like I’m getting in there
4. (.) he’s all right though.

**Stanza 85**: exception to positive interactions with practitioners

1. (.) apart from the health visitor coming around the house.
2. That’s the only bad experience we’ve had with people interacting with him
3. and that was just because/ (.) I don’t think she was really bothered
4. don’t feel emotions kind of thing

**Toni:** busy people, who knows?

**David:** yea (.)

**Strophe 35:** reasons to ask for one-to-one support at school

**Stanza 86**: hope to get one to one support

1. **Toni:** he’s going through the Education, Health and Care Plan process at the moment/, what are your expectations from it?
2. **David**: well, we are hoping from all of that that he gets some extra-help at school
3. so someone can spend one-to-one time with him/ can help him with stuff
4. (1) to try to help develop his speaking and talking.

**Stanza 87**: Rob needs more than help with speech

1. **Toni:** ok, so what that extra-support needs to be focused on for you is the speech and language?
2. **David:** yea, language and understanding.
3. Also, with him having one on one we feel like he’ll be a bit more (1) looked after, if that makes sense.
4. Not that he’s not being looked after now/. It’s more so if there is someone there being one on one with him
5. cause he’s just come home a few times with bumps.

**Stanza 88:** they can’t watch him 24/7

1. **Toni**: Right, ok, well, he doesn’t stop as you said.
2. **David**: he doesn’t stop/. That’s what I mean/. It’s like, what? 20 kids in the class.

**Toni**: yes.

1. **David:** They can’t be watching Rob 24/7.

**Strophe 36:** keeping him safe at home

**Stanza 89**: David watches him at home

1. I know because I have to watch him 24/7 at home (.)
2. And one minute he’s there and the next minute he’s gone/ and you’re like ‘where’s he gone now?’
3. **Toni**: Yes, that is just you and him.
4. **David**: yeah, yeah/. He’s quick/, it’s the problem.

**Stanza 90**: Rob has no sense of danger

1. And he doesn’t watch where he’s going half of the time.
2. He just runs and he doesn’t judge the heights of some things.
3. At his nana’s house there is a table and the amount of times he doesn’t judge how high it is and he just goes ‘cunq’ and knocks himself over (.) and you are like (1)

**Strophe 37:** carers also can get hurt

**Stanza 91**: David has been hurt while keeping Rob safe

1. **Toni:** so it’s support with that

**David:** yea, so

**Toni**: keeping him and others safe.

1. **David**: yea, cause (.) I understand where they are coming from with it
2. cause I watch him at home.
3. I am the one stopping him breaking himself (1).
4. I am the one who gets broken stopping him breaking himself

**Stanza 92**: David lost a molar after being hit

1. He knocked out one of my teeth.

**Toni**: oh goodness

1. **David:** back there. I have a molar missing where he hit me in the face.
2. **Toni**: wow. It must have been a (.) a hard hit.
3. **David**: a wooden truck/ he picked up a wooden truck he was playing with.

**Strophe 38:** the accident

**Stanza 93:** how it happened

1. He swung it like that/.
2. He hit me right in the jaw and cracked the molar/ right down the middle.

**Toni**: oh, goodness.

1. **David**: I had to have it removed (1)

**Stanza 94**: David conclusions on the accident

**Toni**: yea

1. **David**: one of them things

**Toni**: oh dear

1. **David**: it happens/. What can you say?
2. At least it wasn’t from me not brushing my teeth or something like that.

**Toni**: ye

**Strophe 39:** something else Rob is good at

**Stanza 95:** Rob is good at brushing his teeth

1. **David**: That's one thing he’s really good at doing actually: brushing his teeth.

**Toni**: right

1. **David**: He likes brushing his teeth.
2. He would stand at the sink/ and he waits for you to brush his teeth.

**Stanza 96:** he brushes his teeth in a different way

1. **Toni:** I wonder if he likes the sensation/. Some people don’t but perhaps he does.
2. **David**: I was thinking that.
3. He draws in the shower with his toothbrush/

**Toni**: ah

1. **David**: and the toothpaste is a paint to get off the glass

………

[an alarm in David’s phone goes off]. That’s an alarm to tell me to pick Sam from school.

Toni: ok, so you need to leave.

David: no, he’s finished. He finished school yesterday.

Toni: Oh yes, of course. I see, I see. Ok, never mind.

**Part 7: Summary of ways in which practitioners have promoted positive interactions**

**Strophe 40:** good communication with practitioners

**Stanza 97:** practitioners have been good with Rob and friendly with David and Lynn

1. **Toni**: So is there anything else that you would like to tell me or (.)
2. **David:** not that I can think of, no. I think we have covered the experiences we’ve had.

**Toni**: ok (1)

1. **David:** in general, roughly all of it/. They’ve been very good with Rob/ and very helpful and friendly with us
2. **Toni**: that’s really nice to hear

**Stanza 98:** practitioners have conveyed information well

1. **David**: and they’ve conveyed information over well if that makes sense
2. (.) cause sometimes people try to explain things and you are like/ (.) I’ve got no idea what you are talking about

**Toni**: ye

1. **David**: (.) but the times we’ve had conversations (.) with the people/ it’s not too difficult/, you’ve not got lost in what they try to tell you.

**Strophe 41:** getting to know Rob’s teachers is important

**Stanza 99**: being able to talk about Rob and other things

1. **Toni**: What about emotional support, do you think you have (.) been able to build a relationship with/ (.) I don’t know/ perhaps with the nursery nurses, with school staff.
2. **David**: yea, with his teacher/. With his nursery teachers/, we’ve been able to talk to them (.)
3. we found common ground to talk about Rob
4. and even stuff that is not Rob. They ask how the house is coming along and stuff like that so (.)

**Toni**: yes, so that’s (.)

**Stanza 100**: why is important getting to know Rob’s teachers

1. **David**: Which is always nice cause/ (.) you like to get along with people who are going to be looking after your kids, don’t ya?

**Toni**: ye

1. **David**: you want to know that they are friendly and happy people
2. and they’re not (David makes a sound) ‘iiiiiii’

**Strophe 42:** places to go to with Rob

**Stanza 101**: there is not much to do outside school

1. **Toni**: (laughs) definitely. Outside school is there enough emotional support for the family?
2. **David**: I don’t think we do much outside school
3. apart from when we take him to the park, to the play area, so (2)
4. there is not much to do with him to be fair.

**Stanza 102**: places to go to with Rob

1. There is the soft play area in P/ where I took him a couple of times.
2. And he likes to go to the big park/ but it’s just me and him and S (1).

**Toni**: right

1. **David**: take a walk down/. Then, play for a bit/ and bring them home/ but (.) ye (.)
2. I’m sure there are some groups he probably could do if we looked into it (.)

**Toni:** right

**Part 8: accessing groups & support for parents**

**Strophe 43**: ways of finding local events going on without using social media

**Stanza 103**: finding information about events is difficult

1. **David**: That's one of the things as well.
2. Where you find the information about these groups
3. cause half of the time you see information later on
4. and think Sam would have liked to go there or Rob would have enjoyed doing that/ but you found out three days too late

**Toni**: ahh

**Stanza 104**: how to make easier finding information about events

1. **David**: it would be helpful if there was like a big main place with things that are going on in B.
2. This is like a calendar/ you can go and look at everything going on kind of thing.

**Toni**: yes

1. **David**: but there isn’t
2. **Toni**: if there is I don’t know about it/ but, yes, you have a point.

**Stanza 105**: how it would work

1. **David**: It would be helpful, wouldn’t it?
2. You could go like, well, what is happening in July?
3. Well, there is these groups for kids so they will have like a kids’ section
4. and then they could have an adult section

**Strophe 44:** ways of finding local events going on using social media

**Stanza 106**: disadvantages of using social media

1. **Toni**: ye (.) I think F A communicates through Facebook
2. **David**: I don’t use Facebook/. I don’t like Facebook/. I don’t use Facebook (.)
3. **Toni:** I don’t either/ but I have it so I know (.) things that are happening/ but I don’t post anything
4. **David**: my wife’s got it but I don’t like Facebook because of people getting information that they shouldn’t have.

**Stanza 107**: social media could help to find events

1. **Toni:** ye (2) maybe Lynn can see what is in F A’s page.
2. **David:** I’ll mention it to her when she gets in/. She might be able to find it (1)
3. That might be helpful

**Strophe 45:** ways of keeping connected over the summer holidays

**Stanza 108**: it is harder to access information over the summer holidays

1. cause It’s summer holidays now so it’s even harder to get information
2. cause every now and again/ you see information at school/ because they used to put it in the notice boards with things going on

**Toni**: yes, but now…

1. **David**: But now it’s summer holidays so you are not going to see that, are you? (1)
2. **Toni**: social media/ even if you don’t like it/ just going to the webpage, F A posts everything on Facebook

**Stanza 109**: organising how to attend to M group to keep connected

1. **David:** ye, well, we are going to go to the thing on Wednesday with Rob

**Toni**: Good, to M?

1. **David:** ye./ Two till three we’ll probably be doing
2. because Lynn is at work till 2
3. so I can drop Sam off at work/ and she can walk back with him/ and I can bring Rob

**Strophe 46:** ways in which David and Lynn work together

**Stanza 110**: Organising the family is David’s job

1. **Toni**: so you are organised, it’s the logistics of sorting everything out, isn’t it?
2. **David:** it’s always my job that. Lynn she would just have a nap.

**Toni**: right

1. **David:** she would sleep anywhere, her. She fell asleep stood up, waiting in line.

**Toni**: right

1. **David:** I’ve seen it (.)

**Stanza 111**: David and Lynn are of the same opinion on their interactions with practitioners

1. **Toni**: so, do you feel you have enough help with Lynn working and everything?
2. **David**: well, I stay at home and I look after Rob mostly so/ I’m fine with him (.) mostly
3. **Toni:** I mean, what do you think Lynn would be telling me about practitioners?/ Is she of the same opinion as you?
4. **David:** Ye, she is of the same opinion/ cause we discuss all of this all the time.
5. We don’t hold anything back from each other.

**Toni**: that’s great

**Strophe 47:** Honesty in David and Lynn’s relationship

**Stanza 112**: David values honesty between him and Lynn

1. **David**: there is no point
2. **Toni**: Well, you are in it together/. You are a team
3. **David**: Yeah. That’s why we don’t lie to each other.
4. I said to her: ‘I'd rather you don’t lie to me than lie to me.’/ (.) Don’t care about what it is/, I'd rather know the truth about something (.) than be lied about it (.)
5. and it comes out later on, so (2)

**Stanza 113**: they both value telling the truth

1. **Toni:** Is there anything that has happened that makes you think about it?
2. **David:** no, no/. It’s just how we have always been with each other, that.
3. So it’s like (.) just from past experience in life
4. (.) we’ve always thought it’s better to just say the truth.

**Stanza 114**: why Lisa values honesty between David and her

1. The primary example that Lynn uses is: “if I put an outfit on and it didn’t look good, I'd rather you tell me rather than me going out and everybody going like (.) ‘uh’”.

**Toni:** (quiet laugh)

1. **David**: ‘So if something makes me look fat, tell me it makes me look fat’.
2. Don’t just go: ‘yes, it looks fine’ (2)

**Strophe 48:** Lynn experience of reaching out to practitioners

**Stanza 115**: Lynn has also felt supported

1. **Toni:** so, about emotional support also/, Lynn would say the same things?
2. **David**: Yeah, Lynn would say the same thing.
3. She’s had some help and that.
4. She had an issue with breastfeeding Rob when he was a little bit older (.)

**Stanza 116:** the doctor or midwife were able to help with breastfeeding

1. but (.) she asked the doctor about it, I think it was/, or it was the midwife (.)/ I can’t remember which one it was/ (.) doctor or midwife.
2. **Toni:** the midwife would help, but if it is after 6 weeks maybe they weren’t involved.
3. **David:** I think it was a doctor./ I think it was a doctor
4. and he said it was fine
5. So (2) Lynn has breastfed both of them (.)

**Strophe 49:** David talks about Seb and Rob

**Stanza 117**: memories of Seb

1. Seb was very small so he had to get it out of a bottle.
2. He was tinny- tinny/. He was four weeks early.

**Toni**: four weeks?

**David**: Yeah, about that big (gesture).

1. He used to sleep on my chest with his feet dangling

**Toni**: ohh

1. **David:** yes, we used to lie in bed with him on my chest watching the laptop

**Stanza 118**: Seb, Rob and Lynn snoring

1. Just watching him there like that (.)/ and he was snoring.
2. Rob snores/ like a *train*

**Toni**: (quiet laugh)

1. **David**: He gets that from his mum. Yea.

**Strophe:** conclusion. Experiences and practitioners have been positive and helpful

**Stanza 119**: David’s family experiences have been positive so far

1. **Toni**: well. Thank you very much. I think I have asked and we have gone through (.) the experiences.
2. **David**: yea, we’ve had fairly positive experiences with all so far

**Toni:** good

1. **David**: I can’t think of anything bad through Rob going to nursery
2. apart from him getting wet/ which is one of them things

**Stanza 220**: everybody has been friendly, helpful and polite

1. but interacting with people about him and his speech problem
2. and trying to get help for him (.)
3. Everyone’s been great and friendly and helpful and polite.

**Stanza 221**: thanking David

1. **Toni**: good, that is (.) it’s important/. Thank you very much.
2. **David**: It's all right.
3. **Toni:** Let’s stop this.

**Appendix 8 Strophes, stanzas and parts titles**

**Titles of stanzas, strophes and parts of John’s narrative**

**Part 1 groups and nursery**

**Strophe 1:** groups

**Stanza 1:** introductory question about interaction with practitioners.

**Stanza 2:** frequency of the groups

**Stanza 3:** age

**Strophe 2:** starting nursery

**Stanza 4:** timings

**Stanza 5:** coming on by being able to communicate

**Stanza 6:** nursery structure

**Part 2**: **special needs identification**

**Strophe 3:** identification

**Stanza 7:** John’s diagnosis

**Stanza 8:** uncertainty

**Strophe 4:** John’s family

**Stanza 9:** diagnosis in John’s family

**Stanza 10:** John’s mum

**Strophe 5**: practitioners

**Stanza 10**: health visitor

**Stanza 11:** paediatricians

**Strophe 6**: feelings about diagnosis

**Stanza 12**: a relief to have an explanation for others

**Stanza 13**: a diagnosis is more than a label

**Strophe 7**: clarifying why a diagnosis is a relief

**Stanza 14**: when I was a kid, you were just a naughty child

**Stanza 15**: now it’s come on leaps and bounds

**Stanza 16**: John’s experience of his diagnoses

**Part 3: family support**

**Strophe 8:** The understanding of the family

**Stanza 17**: N’s understanding

**Stanza 18:** John and N help each other.

**Stanza 19:** differences between John’s and N’s family

**Strophe 9:** John’s family. Reasons for the role of John’s mum.

**Stanza 20:** John’s mum support

**Stanza 21:** John’s grandad passing

**Stanza 22:** John’s family support when he was a child.

**Stanza 23:** John’s mum understanding

**Part 4: practitioners’ support**

**Stanza 24**: it was absolutely brilliant

**Stanza 25**: paediatrician followed Maddie’s lead

**Stanza 26**: telling ‘no’ to Maddie

**Strophe 10**: remembering who said what.

**Stanza 27:** unable to remember.

**Stanza 28:** I don’t think it was a practitioner

**Strophe 11**: resources available outside nursery

**Stanza 29**: groups and nursery as providers of information

**Stanza 30**: information and courses available on autism

**Stanza 31**: difference between the present time and John’s childhood

**Strophe 12**: applying for support at nursery

**Stanza 32**: the SENDCo is requesting it

**Stanza 33**: reasons for requesting the support

**Stanza 34**: looking at the child’s needs

**Stanza 35**: nursery being proactive leading the process

**Strophe 13**: what helps interactions with practitioners

**Stanza 36**: support for children in local groups

**Stanza 37**: importance of routine

**Strophe 14**: support for parents

**Stanza 38**: it could be better

**Stanza 39**: there is no respite for parents

**Stanza 40**: family provides respite.

**Stanza 41**: people don’t see what happens behind close doors

**Strophe 15**: waiting times

**Stanza 42**: timeframe to see practitioners

**Stanza 43:** what could be done.

**Stanza 44**: resignation

**Strophe 16**: financial pressures

**Stanza 45**: need for diagnosis to go to places

**Stanza 46**: each place uses its own discretion to ask for SEND proof

**Stanza 47**: missing out on things Maddie likes

**Strophe 17**: identifying special needs

**Stanza 48**: health visitor’s role

**Stanza 49**: John’s mum and John knew.

**Part 5: emotional impact of having a child with special needs on John**

**Strophe 18:** John blames himself

**Stanza 50**: emotional response to self-blame

**Stanza 51**: Maddie is gorgeous while acknowledging that bringing her up is difficult

**Strophe 19**: fatherhood skills

**Stanza 52**: people’s judgement on John’s parenthood skills

**Stanza 53**: John’s self- doubt changed to amazement.

**Strophe 20**: N’s point of view

**Stanza 54**: N’s understanding has come on.

**Stanza 55**: N’s attends training to know more about autism

**Part 6: John’s relationship with his father and John’s desire to be different**

**Strophe 21:** a normal life for Maddie

**Stanza 56:** wishing for a normal life

**Stanza 57**: being different to my dad

**Strophe 22:** John’s relationship with his dad

**Stanza 58**: disability is in my dad’s side of the family

**Stanza 59**: The views of John’s father on John and family dynamics.

**Strophe 23:** celebrating my son or daughter

**Stanza 60**: acceptance of disability

**Stanza 61:** I am going to love them and I don’t care about disability

**Strophe 24:** father- daughter relationship

**Stanza 62**: the bond

**Strophe 25**: siblings

**Stanza 63**: wouldn’t care disability or not. They are my children

**Stanza 64**: working out uncertainty

**Stanza 65**: interview ending

**Titles of stanzas, strophes and parts in Kate’s narrative**

**Part 1: reaching out to practitioners and not being taken seriously. Was it because of lockdown?**

**Strophe 1: struggle during lockdown**

**Stanza 1:** introductory question about interaction with practitioners.

**Stanza 2:** things not being picked up due to lock down

**Strophe 2: reaching out to the speech and language therapist**

**Stanza 3:** checking what is ‘normal’ development

**Stanza 4:** help from SALT

**Stanza 5:** starting nursery

**Strophe 3**: pushing and waiting

**Stanza 6**: having to push all the time

**Stanza 7**: Assessing for autism a lengthy process

**Strophe 4:** help is good when we get to see practitioners

**Stanza 8**: moving things forward

**Stanza 9**: helpful support

**Strophe 5**: interactions with health visitor

**Stanza 10**: health visitors had not been involved

**Stanza 11**: finding a health visitor

**Stanza 12**: there wasn’t a relationship

**Strophe 6**: check-ups did not show anything

**Stanza 13**: interactions on the phone

**Stanza 14**: health visitor’s visit

**Stanza 15**: getting help from health professionals

**Stanza 16**: summary of Kate’s narrative

**Strophe 7**: not been listened to by practitioners

**Stanza 17**: concerns were dismissed

**Stanza 18**: I was not taken seriously

**Stanza 19**: lack of advice on concerns about speech

**Strophe 8**: identifying justified worries

**Stanza 20**: finding out if people are worrying unnecessarily

**Stanza 21**: advice from SALT

**Strophe 9**: we followed advice but we were not taken seriously

**Stanza 22**: interactions with L were already happening

**Stanza 23**: concerns were not taken seriously perhaps due to Covid

**Strophe** **10**: evaluation of Kate’s experience

**Stanza 24**: Toni highlights Kate’s experience needs to be heard

**Stanza 25**: evaluating interactions with practitioners

**Part 2: support implemented and how it has worked**

**Strophe 11:** seeking support from practitioners

**Stanza 25**: contacting SALT

**Stanza 26**: contacting I Can

**Strophe 12**: taking Lee to nursery was the right decision

**Stanza 27**: he was getting what he needed at home

**Stanza 28**: but he was missing out on interacting with children

**Stanza 29**: his speech has not improved but he loves it

**Strophe 13**: nursery staff are requesting extra support, it is not just Kate

**Stanza 30**: we have started the process of getting extra help in school

**Stanza 31**: nursery is pushing in the family’s behalf

**Strophe 14:** emotional support is provided by Kete’s family

**Stanza 32**: Is there enough emotional support?

**Stanza 33**: unaware of services providing emotional support

**Part 3: what would be different if Lee is diagnosed with autism**

**Strophe 15:** emotional and practical support needed around autism diagnosis

**Stanza 34**: feelings and knowledge on autism

**Stanza 35**: parenting different with a diagnosis

**Stanza 36**: Kate knows Lee and wants to learn about autism

**Stanza 37**: Kate needs support

**Strophe 16**: two reasons to seek practitioners support

**Stanza 38**: pushing to get early intervention

**Stanza 39**: what do I need to do differently?

**Strophe 17**: gaining help to navigate interactions outside the home

**Stanza 40**: meeting the needs of a perfect boy

**Stanza 41**: how is he going to communicate?

**Part 4**: finding containment and the importance of having someone “fighting your corner”

**Strophe 18:** frustrations and hopes around appointments

**Stanza 42**: Kate’s partner also gets frustrated about waiting

**Stanza 43**: hopes about appointments

**Strophe 19**: Kate pushes because L is her priority

**Stanza 44**: then nothing happens

**Stanza 44**: feeling selfish and frustrated about chasing practitioners

**Stanza 45**: I want the best for him

**Strophe 20**: what needs to happen for practice to improve

**Stanza 46**: how could things be better?

**Stanza 47**: having someone fighting your corner

**Stanza 48**: practitioner’s role to reassure parents

**Strophe 21**: requesting

**Stanza 49**: support during EHC needs assessment

**Stanza 50**: emotional support from nursery

**Stanza 51**: improve communication with practitioners

**Strophe 22**: benefits of attending groups with other parents of children with SEND

**Stanza 52**: How did it feel attending the groups?

**Stanza 54**: reassurance from sharing general parenting experiences

**Strophe 23**: Ending the interview.

**Titles of stanzas, strophes and parts in David’s narrative**

**Part 1: Introduction. Practitioners who have been in contact with Rob and his family**

**Strophe 1:** so far everything’s been very good with Rob

**Stanza 1:** introductory question about interactions with practitioners.

**Stanza 2:** He does not want to talk but everything else is fine

**Strophe 2:** visits to practitioners

**Stanza 3:** referral to the speech and language therapist

**Stanza 4:** visit to the hearing specialist

**Stanza 5:** visit to the paediatrician

**Stanza 6**: conclusion

**Strophe 3**: speech, language and communication needs

**Stanza 7**: Rob’s parents noticed he was not talking

**Stanza 8**: ways in which Rob communicates

**Stanza 9:** confirming suspicion

**Part 2: attending groups for children with SEND**

**Strophe 4:** attending speech and language groups

**Stanza 10:** arranging to attend the groups

**Stanza 11**: knowing what to do

**Stanza 12**: other advantages of attending the groups

**Strophe 5**: effects of Covid

**Stanza 13**: lack of interactions due to the Covid pandemic

**Stanza 14**: getting help during the Covid pandemic

**Strophe 6**: expanding on the groups David has attended with Rob

**Stanza 15**: advice from speech and language therapist

**Stanza 16**: groups for children with SEND

**Strophe 7:** finding out about places to go with children

**Stanza** **17**: information from the groups for children with SEND

**Stanza 18**: exchange of information as belonging to the group

**Strophe 8:** what makes the group better

**Stanza 19**: parents’ interactions

**Stanza 20**: common purpose

**Strophe 9:** interactions between parents, children and with practitioners in the groups

**Stanza 21**: a good level of interaction

**Stanza 22:** overwhelming parents with information

**Stanza 23:** what was helpful in the groups

**Part 3: Not being listened to**

**Strophe 10:** a specific problem

**Stanza 24:** playing with the water and getting wet

**Stanza 25:** getting colds as a result of being wet

**Strophe 11:** David’s solution is ignored

**Stanza 26**: proposing a solution

**Stanza 26:** the situation stays the same

**Strophe 12:** nursery following their rules without knowing Rob cannot work

**Stanza 27:** attendance is ‘not up to the level they want it to be’

**Stanza 28**: in a ‘catch 22’

**Stanza 29**: David’s response to the nursery staff’s phone call

**Part 4: consultations with practitioners**

**Strophe 12**: sorting the EHCP referral process

**Stanza 30**: Getting started with the EHCP referral

**Stanza 31**: nursery staff made the process easy

**Strophe 11:** communicating with practitioners involved in the EHCP process

**Stanza 32**: difficulties of communicating with people who do not know about a situation

**Stanza 33**: talking with the educational psychologist

**Strophe 12:** appointment with paediatrician was surprisingly quick

**Stanza 34**: the appointment came through quickly

**Stanza 35**: receiving the appointment quickly was unexpected

**Strophe 13**: what happened during the paediatrician’s appointment

**Stanza 36**: what the paediatrician did

**Stanza 37**: what the paediatrician found

**Stanza 38**: what the paediatrician thought about Rob’s speech

**Strophe 14:** diagnosis of hypermobility

**Stanza 39**: David was surprised about the hypermobility

**Stanza 40**: what to do next about it

**Strophe 15:** when interactions with practitioners have been negative

**Stanza 41**: practitioners can be arrogant

**Stanza 42**: a bad experience with the health visitor

**Strophe 16:**  what did not work during the visit

**Stanza 43**: what made the interaction a negative one

**Stanza 44**: summary of what happened during the visit

**Strophe 16**: uncertainty on what would happen next

**Stanza 45**: there was no follow-up

**Stanza 46:** there should have been follow-up appointments

**Strophe 17:** David asked the doctor to check Rob

**Stanza 47**: clarifying timings

**Stanza 48**: the doctor checked Rob instead of the health visitor

**Strophe 18:** the doctor had no concerns at that time

**Stanza 49**: the appointment with the health visitor was not going to happen

**Stanza 50**: the doctor said everything was fine

**Strophe 19:** when concerns started

**Stanza 51:** Concerns were identified at nursery

**Stanza 52:** but everybody has been nice to him

**Part 5: emotional and practical support needed**

**Strophe 20:** what could have been better and what has worked

**Stanza 52**: lack of opportunities to interact with others during Covid

**Stanza 21:** helpful practitioners

**Strophe 21:** groups happening at the same time

**Stanza 54**: cannot attend the groups

**Stanza 55**: spread the groups out over the week

**Strophe 22**: help available for parents

**Stanza 56**: David and Lynn are quite self-sufficient

**Stanza 57**: I could get help if needed

**Strophe 23**: being able to have a couple of hours for themselves

**Stanza 57**: respite

**Stanza 58**: nursery hours

**Strophe 24**: paying for nursery hours was a waste because he could not attend

**Stanza 59**: paying for nothing was annoying

**Stanza 60**: he could not go because he was ill after being wet

**Stanza 61**: changing the nursery hours due to financial costs

**Strophe 25**: clarifying when Rob will go to school

**Stanza 62**: next year he will attend nursery

**Stanza 63:** going to school with his brother

**Part 6: Rob’s needs and strengths. Ways to promote Rob’s language skills and keep him safe**

**Strophe 26:** the main concern is that Rob does not speak

**Stanza 64:** David would like practitioners to be able to help Rob to speak

**Stanza 65**: he gets frustrated by it

**Strophe 27**: it is difficult to understand Rob’s wants and needs

**Stanza 66**: thinking about what he wants

**Stanza** **67**: he communicates but sometimes he gets frustrated

**Strophe 28**: an example to illustrate the problem

**Stanza 68**: Rob wants an sliced apple

**Stanza 69**: David got there in the end

**Stanza 70**: Rob does not focus on using different means of communication

**Strophe 29:** David’s business to help Rob’s progress

**Stanza 71**: Rob’s progress

**Stanza 72**: what he can do

**Stanza 73**: David is always busy

**Strophe 30:** benefits of spending more time in nursery

**Stanza 74**: more time in nursery would help David

**Stanza 75**: it would also help Rob

**Stanza 76:** a win-win situation

**Strophe 31**: evaluation of appointments with practitioners

**Stanza 77**: appointments and help received have been good

**Stanza 78**: change of health centre

**Strophe 32:** help received has been good but sometimes David is tired to listen because Rob does not care

**Stanza 79:** help received from practitioners has been mostly good

**Stanza 80:** feeling tired

**Stanza 81**: Rob does not care

**Strophe 33:** evaluation of interactions with nursery staff

**Stanza 82**: one occasion in which school has not been good

**Stanza 83**: apart from that exception school has been helpful and friendly

**Strophe 34:** Rob does not stop but apart from the health visitor everybody has been good with him

**Stanza 84**: Rob never stops

**Stanza 85**: exception to positive interactions with practitioners

**Strophe 35:** reasons to ask for one to one support at school

**Stanza 86**: hope to get one to one support

**Stanza 87**: Rob needs more than help with speech

**Stanza 88:** they can’t watch him 24/7

**Strophe 36:** keeping him safe at home

**Stanza 89**: David watches him at home

**Stanza 90**: Rob has no sense of danger

**Strophe 37:** carers also can get hurt

**Stanza 91**: David has been hurt while keeping Rob safe

**Stanza 92**: David lost a molar after being hit

**Strophe 38:** the accident

**Stanza 93:** how it happened

**Stanza 94**: David conclusions on the accident

**Strophe 39:** something else Rob is good at

**Stanza 95:** Rob is good at brushing his teeth

**Stanza 96:** he brushes his teeth in a different way

**Part 7: Ways in which practitioners have promoted positive interactions**

**Strophe 40:** good communication with practitioners

**Stanza 97:** practitioners have been good with Rob and friendly with David and Lynn

**Stanza 98:** practitioners have conveyed information well

**Strophe 41:** getting to know Rob’s teachers is important

**Stanza 99**: being able to talk about Rob and other things

**Stanza 100**: why is important getting to know Rob’s teachers

**Stanza 101**: there is not much to do outside school

**Stanza 102**: places to go to with Rob

**Part 8: accessing groups & support for parents**

**Strophe 43**: ways of finding local events going on without using social media

**Stanza 103**: finding information about events is difficult

**Stanza 104**: how to make easier finding information about events

**Stanza 105**: how it would work

**Strophe 44:** ways of finding local events going on using social media

**Stanza 106**: disadvantages of using social media

**Stanza 107**: social media could help to find events

**Strophe 45:** ways of keeping connected over the summer holidays

**Stanza 108**: it is harder to access information over the summer holidays

**Stanza 109**: organising how to attend to M group to keep connected

**Strophe 46:** ways in which David and Lynn work together

**Stanza 110**: Organising the family is David’s job

**Stanza 111**: David and Lynn are of the same opinion on their interactions with practitioners

**Strophe 47:** Honesty in David and Lynn’s relationship

**Stanza 112**: David values honesty between him and Lynn

**Stanza 113**: they both value telling the truth

**Stanza 114**: why Lisa values honesty between David and her

**Strophe 48:** Lynn experience of reaching out to practitioners

**Stanza 115**: Lynn has also felt supported

**Stanza 116:** the doctor or midwife were able to help with breastfeeding

**Strophe 49:** David talks about Seb and Rob

**Stanza 117**: memories of Seb

**Stanza 118**: Seb, Rob and Lynn snoring

**Strophe:** conclusion. Experiences and practitioners have been positive and helpful

**Stanza 119**: David’s family experiences have been positive so far

**Stanza 220**: everybody has been friendly, helpful and polite

**Appendix 9. Summaries of my interpretations of the narratives**

***Summary of my interpretations of John’s narrative***

**Going to nursery**

John told me that going to school has been greatly beneficial for Maddie because school staff have taught her to communicate her needs and wants through sign language and using pictures as she is non-verbal.

**Identification of needs**

The possibility of having a child with SEND has always been in John’s mind because it runs in his family and he has several diagnoses. John’s mum also had shared that she thought there was ‘something there’. They knew there was a disability when the health visitor told John that Maddie has sensory needs.

**Diagnosis**

John described the sensory needs and autism diagnosis as a “relief” because he can explain to other people why Maddie might not comply with society’s expectations of behaviour in social situations

In John’s narrative disability is described in negative terms but he defends the need for a label so the child is not considered to be naughty.

John explores his experience of being labelled with “ADHD, autism, dyslexia, dyspraxia and Aspergers” in the 90s. At that time “you were just a naughty child”. He seemed to link these experiences in the past to his mental health now.

John’s wife seems to be good support for his emotional needs. She works with adults with autism and ADHD, she understands John and he can be open with her.

John values positively having a “massive” spectrum of conditions nowadays instead of being diagnosed with one condition like when he was a child. He seems to suggest that support must be orientated towards meeting needs. This would be in line with current legislation in which support is provided according to need and not a diagnosis of a condition.

**Behaviour**

Maddie’s distress seems to be a big worry for John. John and his wife take the brunt of it when she gets dysregulated at home. I think a different understanding of these behaviours by society would help John to reach out for support without judgement and relieve the emotional distress they might produce in him.

**Describing ‘normal’**

John seems to link ‘normal’ with behaving in a rational way. However, when he reflects on what normality means, he describes ‘normal’ in a highly personal way. Normal is related to John’s identity as a father. Normal is not being like his dad. It is “being in the picture” for his daughter.

**John’s identity as a father**

John became upset when he explained that he blames himself for Maddie’s way of being. However, he talked about others and his own amazement at how well he looks after Maddie. Fatherhood seems to bring John fulfilment and satisfaction. I think that practitioners and other people’s understanding of this overarching narrative of love would help valuing disabled people in society.

I found it moving listening to John’s description of his bond with Maddie and the satisfaction fatherhood brings him. John’s love for his daughter seems to spill over the words. I think poetic language would have been best suited to contain this meaning.

**Understanding Maddie**

John’s family seem to have an understanding of Maddie’s motivations, thoughts and feelings because they have dealt with disability all his life.

John also appreciates the ability of practitioners to enter Maddie’s world and follow her lead during a paediatrician’s appointment, although he grapples with the need to abide by social conventions of good behaviour when she tried to draw on the doctor’s desk.

**Feeling safe**

John highlights that his mum is his and his wife’s support. His mum seems to be providing a safe space for them. For example, John’s mum joins John and his wife in appointments with practitioners. I think she is providing John and his wife safety to express the emotions attached to these appointments. She also asks appropriate questions, which might shift power imbalances between practitioners and parents.

**What could be better in the current SEND system**

Firstly, John identified waiting times to see different practitioners as an area which needs to improve. He asks for waiting times to be cut “a bit”, instead of disappearing.

Secondly, John notes the need for respite for him and his wife. He asks for “just a couple of hours to themselves”.

Thirdly, he acknowledges that finances put pressure on the family and asks for clarity on what activities he can access without charge. However, he does not ask for financial support.

I think his reticence to ask for more in these areas might be related to the stigma attached to receiving help.

**Uncertainty**

At the end of the narrative, John talked about his plans around having another child depending on Maddie’s development. This might explain his attempts to work out the possibilities of having a child with disabilities. He seemed to conclude that he would have to sit with uncertainty.

***Summary of my interpretations of Kate’s narrative***

**Pushing all the time**

Kate introduces the idea that she had to “push all the time” despite that it seems to be at odds with Kate’s preferred sense of self and identity.

The love and parental responsibility Kate feels for Lee are palpable in her narrative and she does not manage to hide that her struggle to contact practitioners arouses strong emotions within her. I interpret that she is consciously giving up her sense of being reasonable to get help for her child.

**Current SEND system**

Kate seems to reason that she has to push because early identification is needed to achieve better outcomes. This discourse is reflected in current legislation. However, it has also been criticised because it might neglect the implementation of provision in the child’s context to favour within-child strategies (Burman, 2017).

**Feeling safe**

I think Kate is looking for reassurance and a safe space in her interactions with practitioners. Lack of communication hinders this. Williams (2013) proposes that talk by professional practitioners has the potential to help to regulate emotions leading to the formation of knowledge and mutual development or it can lead to the opposite effect if emotions are not acknowledged.

**Knowledge and power**

Kate notes that she did not feel that practitioners were taking her seriously on occasions, they were not listening to her. At the same time, she justifies it by articulating her lack of knowledge and power as a first-time mother and also articulating that parents can worry unnecessarily.

Power differentials between parents and practitioners have been identified by research (Douglas et al, 2022). In this situation, Kate seems to look for allies who can “push on our behalf” to help Lee. The staff at Lee’s nursery seem to fulfil that role.

**Diagnosis of autism**

Kate seemed to think that if Lee is diagnosed with autism she will need to parent differently. However, she seems to fully accept Lee’s way of being so she is already able to parent him from ‘where he is at’.

It seems that Kate perceives she would need to change her parenting if Lee is diagnosed with autism because of the challenges he will have to overcome when he is older and needs to communicate with people outside the home.

Billington (2000) illustrates different constructions of autism. One of them is an expert account in which autism is seen as a within-child deficit. A contrasting account views autism as a relational condition in which adults help by opening their understanding of the child’s world, their feelings and experiences. These different approaches indicate that practitioners have a responsibility to construct Lee’s autism (if he is diagnosed) with Kate to increase her agency to parent him.

**Uncertainty**

I have also reflected on the voice of uncertainty expressed in Kate’s narrative as a worry arising from the new challenges and situations looming as Lee grows up. Once again practitioners need to play a role in containing these feelings (helping Kate feel safe and protected).

***Summary of my interpretations of David’s narrative***

**Everything is fine**

In response to the question I asked: ‘what have your interactions with practitioners been like?’ David’s narrative starts by stating that they have been very good, although Rob does not want to talk, which has been difficult.

He explained that Rob could articulate long words such as “dinosaur” but he does not use his words to communicate with purpose. David’s interpretation of Rob “not wanting to talk”’ may be in line with affective neuroscience, which proposes a model in which emotions and thoughts are mediated by our interactions with the external world.

Rob’s teachers told David that apart from being behind with his speaking everything else was fine. They asked for one-to-one support to help with his language skills and because Rob had no sense of danger so additional support was needed to keep him safe.

**Maintaining positive interactions with practitioners**

Sometimes David finds information given by practitioners overwhelming. David looks after Rob “24/7” so he knows Rob best. As a result, advice from practitioners needs to empathise with this to be accepted and helpful.

David summarises different reasons for having positive interactions with practitioners. He appreciates that everybody has been good with Rob, friendly to him and Lynn and they have not overwhelmed them with information. The practitioners’ friendly approach and conveying helpful information seem to alleviate anxieties by responding in an accepting and friendly way. There are many examples in his narrative indicating he finds this helpful.

**When interactions go wrong**

David gives also an example of a negative interaction with the health visitor. When David summarises why this interaction was negative, he told me that the health visitor did not show emotions and came across as condescending.

David describes another negative interaction related to not being listened to when he asked nursery staff not to let Rob play with water in winter because it was making Rob become ill frequently.

**What could be better in the SEND system**

David also talks about practicalities in his interactions with practitioners which have been helpful, such as not having to wait for the appointments with the paediatricians. Issues which David identified as something to be improved could be that “there is not much to do with Rob” in the local area. The problem seems to be that sometimes groups happen at the same time or David cannot find information about them on time to attend. It seems that not using social media and the summer holidays compounds this issue as they tarnish connection with services available.

David only can think of one thing he needs help with: looking after Rob for a couple of hours to give him and his wife respite from the intensity of looking after Ryan. David told me that increasing Rob’s hours in nursery would be beneficial to give him and Lynn respite and promote Rob’s language and communication skills. However, this was not happening because increasing the hours implied financial costs. David seemed keen to give Rob as many opportunities as possible to talk and interact with others.

**David’s identity as a father**

The idea that looking after Rob is exhausting and that David is tired is presented on different occasions throughout the narrative. He takes responsibility for organising childcare as his children's main carer. He seemed to introduce a comical note to his wife’s contribution to their children’s care but he valued being able to discuss his views and experiences with Lynn openly and sharing similar views. I feel that David and Lynn’s shared understanding of their children’s needs will protect David from possible negative outcomes reported in the literature when mothers provide care for their children without enough support.

Rob seemed to embrace his nurturing role bringing up his children. He was building their house and he showed emotional responsibility in his efforts to attune with Rob’s wishes and needs.

I perceive that David went beyond describing the difficulties of caring for Rob. A prominent narrative was his dedication to looking after him. His commitment to finding ways forward to understand and communicate with Rob was pitted throughout the interview, which brought the profound bond they share to the fore.

David seemed to have identified that practitioners and others being friendly and nice to Rob will make a positive difference to his life so he valued positive interactions with practitioners who listen to and accept him and his family.