BEING ‘MUM’: APPROACHING THE SUBJECTIVITY OF MOTHERS OF DISABLED CHILDREN AS BECOMING TO EXPLORE EDUCATION INCLUSION AND EXCLUSION

by

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ABSTRACT

This postqualitative research inquiry, which has been influenced by the researcher's own experiences as a mother of a disabled child, offers alternative ways of thinking about mothers of disabled children and the inclusion of disabled children that extend beyond the categorisation of mothers being categorised within stable subject positions, and challenges the binaries often presented within existing research exploring inclusive education. Relying on a relational process ontology, the inquiry shifts the focus from individual agency to understanding the subjectivity of mothers of disabled children as emerging through a process of co-constitution within shifting multiplicities. Specifically, this thesis explores mothers' experiences of the inclusion of disabled children within a framework of relationality and connectivity, to map the assemblages within which parents of disabled children and pupils labelled with SEND are entangled.

Philosophy is employed as a means of research and a way of viewing the world. The onto-epistemology employed underpins all aspects of the inquiry. Embracing a feminist new materialist and posthumanist orientation, the thesis 'felts' (Springgay, 2022) philosophical and empirical research approaches as it puts theory to work. This challenges the perceived binary between philosophy and empirical research, fostering an entanglement of co-emergence and co-composition. By adopting this orientation, it becomes possible to dismantle rigid boundaries that position some humans as less than, without relying on negative critique, instead offering generative and affirmative possibilities that can lead to new meanings of difference and inclusion (Naraian, 2020; Braidotti, 2009).

The methodological approach was inspired by Blanchot’s conception of conversation as ‘plural speech’ (Blanchot, 1993). This form of conversation does not seek to ‘annex the other’ or study them ‘as a thing’, instead it is conditioned by ‘a relation of infinity and strangeness’ (Bojesen, 2019:653). What matters is the movement of thought that takes place, rather than what is said or subject development. Seven mothers of disabled children were engaged in ongoing conversations over a period of 12 months, each initiating an exploration of inclusion with a chosen prompt. These ongoing conversations allowed an exploration of uncertainty, contradictions, and tensions, through which it becomes possible to think differently about maternal subjectivity and mothers' approaches to their disabled child's inclusion in education. To avoid reducing conversations to mere data to be dissected, the thesis employs the creative research methods of both collage and poetry. By entangling visual and written materials new meaning-making and knowledges emerge, enabling an affective engagement with the materiality of the subject matter. These are presented throughout the thesis as moments of disruption, intended to supplement and supplant the written narrative, as different displaced and juxtaposed elements that jostle for attention (Morgan, 2000).

The substantive chapters are presented as three theoretically informed ‘threads’ that can be woven together in different ways to explore the assemblages that mothers of disabled children are entangled within that shape possibilities for inclusion and exclusion within education. These chapters discuss disability activist affordances as a way of theorising what mothers of disabled children *do*, rather than who they are, the materiality of documentation and what it produces, and a more relational approach to thinking about both belonging and inclusion.

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Kieron – I blame you for suggesting in 2013 that I undertake a short course, knowing that I cannot do things by half. Thank you for the never-ending supply of books and for being my biggest supporter. **Tanzie** – my moo, you inspire me every single day with your confidence, your strength, and your incredible hugs. Keep being you! You will change the world in ways I can only begin to imagine. This has always been for you. **Caspar** – now maybe I won't work night and day, seven days a week! Thank you for keeping me in Maltesers and Haribo.

This inquiry has not been undertaken in isolation. Not only have I been privileged to read and learn from incredible scholars and mothers of disabled children who have gone before me, but also I have made such valuable friends whose support I continue to value. I am running out of room so forgive me for not naming everyone, but I especially want to thank **Neetha, Jules, Winne, Tanya, Charlotte, Lucy, Philippa and Jo** for your friendship, your passion and your challenge.

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PART ONE

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LIST OF ABBREVIATIONS

AP	Alternative Provision
DfE	Department for Education
EHCP	Education, Health and Care Plan
LA	Local authority
LSA	Learning Support Assistant
MAT	Multi-Academy Trust
SEN	Special Educational Needs
SEND	Special Educational Needs & Disabilities
SENDIST	Special Educational Needs and Disability Tribunal
SENDCO	Special Educational Needs Co-Ordinator
TA	Teaching Assistant

1. INTRODUCTION

1.1 Introducing the research inquiry

I am ‘mum’.

I attend meetings with professionals where I lose my name and am simply referred to as ‘mum’. I am there to play a role: I am ‘mum’. This role sits in contrast to the professionals on the other side of the table, who have an assumed level of authority, expertise, and decision-making power. These meetings are normally scheduled at a time that suits those organising them, whereas we receive notification of the time and date. The professionals decide how long we need for the meeting, who should attend, and set the agenda. Everyone knows the rules of the ‘choreographed dance’ that is about to be performed. ‘Mum’ is expected to turn up to join the dance when needed and must not step out of line[1]. Following and in between meetings, I receive emails and reports which describe how ‘mum’ feels or what ‘mum’ wants, for example ‘mum feels that her daughter struggles with friendships’. This contrasts with professional opinion in reports, which is seen as objective and therefore carries more weight.

As ‘mum’ I find myself having to advocate for one of my two children at a ‘level of frequency and complexity [that] other parents do not usually face’ (Ryan & Runswick-Cole, 2009:43-

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[1] Over the years my husband and I have attempted to introduce our own moves, improvisations and slight missteps that disrupt the choreography of the dance. For example, in one meeting, we asked to start the meeting, and our daughter made a presentation using the school marking scheme WWW/EBI (What went well/Even better if). Such actions disrupt and unsettle, enacting a slight, albeit temporary, shift in the power dynamics in the room.

44). This is because my daughter is disabled. Through my personal experiences, my study, work, and volunteering, I know I am not alone. There are many other ‘mums’ out there, having to become legal experts, heading into meetings armed with annotated reports and piles of paperwork, worrying about their child’s education and future, spending hours wondering if they could have done more (often in the middle of the night).

This inquiry is *for them*.

This inquiry has been conducted *with them.*

My hope is that this inquiry will *make a difference* for them and for their children.

1.1.1 Why I have undertaken this inquiry

I have two children, both of whom are now adults and in the final stages of their formal educational journey. My son is not disabled, my daughter has Down syndrome. For my son, there were various expectations placed on me during his education, eg. completing forms to state a preference for school placement, supporting school events, attending parents’ evenings, encouraging him to do homework and revision, and contributing time or money to fundraising efforts. The demands and expectations placed on me as a mother of a disabled child were significantly greater. From the very earliest days of my daughter’s life, I became a therapist, following instructions from a physiotherapist to help her build co-ordination and muscle strength. I juggled multiple appointments with medical professionals, who measured and monitored her growth and progress against expectations, whilst also attending Early Intervention groups to learn how to support her optimal physical and cognitive development.

Our story of rejection and exclusion in education also started early, when trying to secure her pre-school place at 18 months old. On hearing the words ‘Down syndrome’, the first pre-school I spoke to immediately suggested that I visit other local pre-schools that might be more suitable. Securing a place in school required a complex and lengthy assessment process, where professionals were asked their opinion on what type of education would be best for her. I taught myself the legal framework, attended courses, and read countless books and articles. I have been supported by other mothers and have supported others in return by co-founding a Down syndrome support group, being Chair of our local Parent Carer Forum, and undertaking a range of paid and voluntary roles that train or provide information and support. I returned to study in 2014, first undertaking an Education Studies degree, followed by an MA in Philosophy of Education, through which I wanted to understand more about education and inclusion, my role as a mother of a disabled daughter and the choices we were making. I was especially curious about why some parents advocate for mainstream education and why others might fight for specialist provision. This doctoral inquiry is a further step in this journey.

My daughter and I have engaged in numerous research studies, interviews, surveys/questionnaires, focus groups and observations. However, my role as a mother of a disabled child alongside my engagement with philosophy and previous research led me to attempt something new when undertaking this doctoral inquiry. When reading published research, I often felt that it failed to articulate the complexity of my life and the ongoing challenges that my husband and I have faced when making decisions about the education our daughter should receive. The results emerging from traditional research approaches have often felt simplistic, not allowing for the tensions and contradictions that I have personally experienced when engaging with a wide range of professionals, in often complex and challenging discussions or negotiations.

There can be a significant 'distance between the experience of being a mother and the experience of being the mother of a disabled child' (Ryan & Runswick-Cole, 2008:199). Those who have not lived through it may struggle to understand the complexities of bringing up a disabled child and the different ways you need to engage with the education system (Ryan & Runswick-Cole, 2009). I wanted to bring these complexities to the fore, to highlight the important role that mothers play in their child's education and inclusion, and the multiple factors that impact on the decisions they make about their child's education as they 'operate within a disabling set of practices' (Ryan & Runswick-Cole, 2008:201). Mothers must engage within a 'narrow and inflexible' legislative framework and system that structurally 'enforces perceptions of disability as negative and undesired' (Ryan & Runswick-Cole, 2008:206). Although all families engage in education and might need support at some time to navigate the education system, there is a 'professional logic' dominated by deficit thinking that particularly shapes the interactions that parents of disabled children navigate (Bosteels et al., 2012:984). Ryan & Runswick-Cole (2009:47) have suggested that parent-professional interactions can both challenge and be catalysts of change in mothers' self-identity, and the advocacy work they must undertake for their disabled child requires a ‘different kind of mothering’.

There have been numerous studies undertaken with parents of disabled children, as I will go on to discuss below, yet still mothers continue to have to have a daily fight for the right to a meaningful education for their child. Generations of mothers of disabled children have told stories in hope it will lead to reform (Runswick-Cole et al., 2022). Yet, stories alone are not enough to be a catalyst for change (Runswick-Cole & Ryan, 2019). It became important to me to find a way of approaching research that does not simply (re)produce ‘comfortable and familiar tales using tried and true measures and methodologies’ (Lennon, 2017:535). Instead of ‘sticking with what has become familiar’ (Flood, 2019:48), this research therefore uses a non-traditional approach to explore the ongoing othering and exclusion of disabled children in education. This inquiry is an experimentation, designed to allow ‘different understandings, different feelings and different subjectivities to emerge’ (Lennon, 2017:535).

1.1.2 Limitations of previous research

Decades of consistent findings

Undisputedly there is a ‘substantial body’ of academic research that offers ‘insight into the lives of disabled children and their families’, most of which generated in the last 50 years (Brett, 2020:826). Parents, especially mothers, are seen to offer an ‘essential dimension’ or perspective when exploring the lives or needs of disabled children (Brett, 2020:826). Much of the research relates to the wider family experience of life with a disabled child, parental stress or the additional ‘challenges’ that life with a disabled child might have on relationships, work-life balance, or finances (Parchomiuk, 2020; Enea & Rusu, 2020). Green et al.’s (2016) review of previous research suggests that whilst there has been considerable attention paid to the complex experiences of parenting disabled children since the 1960s, similar issues continue to be reported in research findings. They raise concern that new research is just ‘reinventing the wheel’, covering the same topics whilst neither citing it nor building on it to paint ‘a more complete and nuanced picture’ of what it means to parent a disabled child (Green et al., 2016:279). I wish to avoid this here.

Similar patterns can be seen in research with mothers about the education and inclusion of disabled children. There are numerous studies, going back decades, that relate to parents’ expectations, understandings, or experiences of education and inclusion (eg. Erwin & Soodak, 1995; Jenkinson, 1998; Male, 1998; Grove & Fisher, 1999; Lalvani, 2013; Shurr et al., 2021; Cologon, 2022; Satherley & Norwich, 2022). As Shurr & Minuk (2023) describe most research undertaken with parents utilised interviews to explore their experiences or quantitative methodologies such as surveys and rating scales. They, like Green et al., also discuss how recent research is producing consistent findings with previous research. Clearly children and young people categorised as having Special Educational Needs & Disabilities (SEND) continue to have negative experiences within the education system. Whilst anticipating that many of the recurring themes evident in previous research would also emerge in this inquiry, my aim was to design a non-traditional approach to inquiry that would lead to additional avenues to explore, to disrupt the status quo.

One example of a recurrent theme is ‘belonging’. Almost thirty years ago, Erwin & Soodak (1995:139-140), drawing on semi-structured interviews with mothers of disabled children, identified themes such as ‘a sense of belonging’, the need for acceptance by society, and the journey to parental advocacy. Similarly, in Lalvani’s research almost two decades later, which also utilised semi-structured interviews, mothers ‘expressed beliefs about where their children would “fit in” or where they might “belong”’ and saw mainstream education ‘as an indicator of societal acceptance of their children’ (2013:439). More recently, Cologon (2022:404) discussed how ‘belonging emerged as a strong theme in the participants’ perspectives on what inclusion means’ in interviews with parents, where belonging is understood as ‘being welcome, being a valued community member, and experiencing togetherness’.

Due to the nature of the research approaches taken in previous studies, there has been limited opportunity to explore the concept of belonging in greater depth, or the impact that not belonging might have on the decisions mothers make. The relationship between inclusion and belonging is not questioned, nor is the link between belonging and exclusion explored in any depth. By introducing an alternative approach to inquiry, this doctoral inquiry offers a critical exploration of the concept of belonging and its close relationship to inclusion, drawing together previous research with mothers, the theorising of disabled scholars, and the experiences of the mothers who took part in this inquiry.

Reliance on binaries or stable identity positions

Discussing research about maternal subjectivity and disability, Goodley (2007:146) describes how research has identified a ‘host of subject positions occupied by parents and/or mothers: fighting parents, disabling parents, tragic parents, empowering parents’. However, he contends that these suggested stable and bounded subject positions can lead to an analysis that ‘makes claims about who and how that “parent is” at that time’, rather than recognising that parents defy categorisation and that ‘the process of becoming – or not yet being – forms an essential part of parents’ engagement with and resistance to a whole host of disability knowledges’ (Goodley, 2007:146). Goodley argues that it is necessary ‘for a reading of parental narratives that augments the resistance, construction and becomings of parenting’ (Goodley, 2007:146). Yet, almost two decades later, simplistic categorisations and labels about mothers of disabled children continue to be used in both research and practice. As Stober & Franzese (2018:76) write, the literature about mothers of disabled children does not consider ‘the multiple identities mothers may hold’. For example, many dominant conceptions of motherhood are based on the ‘good’ white, heterosexual, middle class mother, consequently overlooking mothers who fall outside of this description who might face greater marginalisation. When ‘sharply delineated’ categorisations or binaries are used to portray motherhood, it can further work ‘to valorise good mothers while simultaneously punishing those that deviate from the idealised norm’ (Williamson, 2023:16). It is therefore necessary to recognise how mothers’ experiences are complex and multifaceted, rather than relying on rigid and enduring representations or categorisations. Instead of looking at marginalisation ‘in spheres related to their identities’, this research does not attempt to stratify parental experiences (Stober & Franzese, 2018:85). Marginalisation and exclusion can happen in a range of different spaces, and how it is experienced can also change over time. Accordingly, it is necessary to explore 'layered' challenges and shifting identities (Stober & Franzese, 2018:86), rather than relying on 'reductive character tropes' (Williamson, 2023:17). This inquiry responds explicitly to this call and has been designed to employ methodological and analytical approaches based on 'an epistemology of becoming' (Goodley, 2007:157). By designing an inquiry that recognises maternal subjectivity as becoming and multiple, new knowledges emerge relating to documentation and the activism of mothers of disabled children.

Using poststructural or posthuman philosophies within traditional humanist methods

Allan (2008:5) contends that poststructural theories[2] provide 'an escape route out of abandonment and defeat' by offering a 'fresh take' on the challenges of inclusion within an ethically responsible research agenda. She suggests these theories offer a shift away from hierarchical knowledge to 'multiple connections, lines and points of rupture' which can move in unpredictable and messy ways, allowing new forms of knowledge about inclusion to emerge (Allan, 2008:60). As Dillet (2017) describes, poststructuralism has had tremendous effects on research in the humanities and social sciences. Poststructural theorists have suggested that 'to know reality means to 'subjectivise' knowledge rather than objectify it'

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[2] Poststructuralism emerged in philosophy in the 1960s and 1970s. It is associated with French theorists including Derrida, Foucault, Barthes and Baudrillard. This philosophical movement questioned notions of objectivity, universal truths, and binary oppositions, instead focussing on the role of language and discourse in the production of the subject. The work of Deleuze & Guattari is also often associated with poststructuralist thought, though their work is sometimes seen as more radical, introducing concepts such as the rhizome which draws attention to multiplicity and non-linearity.

and they have displaced the idea that a ‘a value-free actor (a subject) can know something by adopting a position of exteriority’ from which they can uncover the essence or truth about reality (Dillet, 2017:517-8).

Posthumanist thought emerged later than poststructuralism, similarly critiquing stable categories and humanist perspectives and understandings of subjectivity. As Bozalek & Zembylas (2016:193) describe, it ‘builds on the epistemological and political foundations of anti-humanism, postcolonialism, post-anthropocentrism, anti-racism and material feminisms’, offering critique to ‘a disembedded liberal humanism, with its assumptions of a society with equally placed autonomous agents and rational scientific control over others’. Instead of recognising humans as the most important beings in the world, posthumanism de-centres the human and recognises subjectivity as produced in ‘intra-action’ (Barad, 2007:33) with human and non-human entities. Braidotti (2013a:13) suggests that posthuman theories need new approaches to research to understand ‘the multi-layered form of inter-dependence we all live in’ and to ‘help us think the unthinkable’.

In recent years, poststructural, new materialist and posthuman philosophies and theories have been employed within disability studies, to challenge stable identity positions and to challenge artificial binary distinctions (eg. medical/social model or nature/culture). These theories draw attention to ‘the ways in which individuals “become” disabled through subjective lived experience in which bodies and culture interact in complex ways’ (Green et al., 2016:264-265). As Flynn & Feely (2023:102) suggest, ‘new-materialism is a valuable theoretical lens as it is equipped to deal with the corporeality of impairment and the embodiment of self, as well as surrounding material worlds within which disabled people are located'. Using these theories demonstrates 'a commitment to not forget the cultural, social, lingual and discursive lines through which disability also occurs' (Flynn & Feely, 2023:114). However, although such theories have been employed in research with parents of disabled children for a decade or more, and despite their different ontological starting point, research outputs continue to bear similarities to those of previous decades (Green et al., 2013;2016). I contend that this could be because the studies in question continue to draw on traditional research methods, such as interviews, observations, and case studies (Green et al., 2013;2016) rather than using the philosophical theories to also shape the research approach. This potential ontological mismatch that we see in much of the current scholarship can therefore fail to move the inclusion debate forward, as the research does not fully utilise the generative nature of philosophical inquiry, which allows researchers to explore concepts in depth and for new understandings to emerge.

In traditional qualitative research methodologies, researchers are required to identify a question, design a study, collect data through a range of methods, and then this needs to be translated or coded into themes that emerge, to produce knowledge in the form of words. This relies on the notion of 'a self-contained human with an identity who retains a separate existence throughout a research study' (St. Pierre, 2023:21). However, when you begin with the immanent ontology of poststructural theory, this challenges the idea of the 'speaking subject' who can be interviewed and observed in empirical research (St. Pierre, 2023:21-2), suggesting that a different approach to undertaking inquiry is required for the theories to be put to work to produce something new. Whilst not discussing SEND or inclusion specifically, Hodgson & Standish (2007:310) raise concerns about the way that poststructuralist philosophy is sometimes applied within mainstream educational research, suggesting that there is a superficial relationship between poststructural theory and the 'ideas it draws upon and makes great claims of'. Instead, they argue, any educational research informed by poststructuralist theories requires 'a differently oriented focus on the self' and an understanding that theory is more than an 'inert' tool to be used; instead, the philosophical theories need to become 'the means by which the researcher relates to the world' (Hodgson & Standish, 2007:325).

Further supporting the need to attempt a new approach to inquiry, Naraian (2020) argues for an approach to researching inclusion that recognises how learners are entangled in different assemblages within which they are constituted, which materialises some students as more normal or capable than others. She suggests that inclusion should be explored as a phenomenon that 'is always already entrenched in the material conditions of its enactments' within multiple assemblages (Naraian, 2020:10-11). She suggests that it is 'via such ongoing mattering that differences are enacted', where subjectivity is emergent within a 'web of entanglements' where concepts such as parent involvement 'can never be presumed to be fully known; instead they remain fluid, their shifting forms registering their multiple entanglements' (Naraian, 2020:15-6). Goodley et al. (2014:353) also argue that, due to their nature, both mothering and disability have the potential to disrupt the notion of a 'self-centred subjectivity, allowing for an expansion of how we understand ourselves in relation to others. This inquiry therefore recognises that we are all constituted through entanglement with one another and within an assemblage that includes the human and non-human and an orientation where I, as researcher, ‘remain continually unknowing’ whilst ‘seek[ing] more expansive understandings of inclusion’ (Naraian, 2020:16).

Naraian (2023:190) argues that when taking up a posthumanist approach to research, ‘the very premise of “data” and related notions of “data collection” and “data analysis”’ are questioned. Yet, she contends, disability studies in education ‘continues to privilege the humanist values that has undergirded much of educational research’ instead of designing inquiry that recognises students as ‘dynamic and continually becoming’ (Naraian, 2023:191). This argument by Naraian (2023) further supports my aims within this inquiry to design research that does not rely on humanist values that are exclusionary to learning-disabled people or research approaches that are based on humanist underpinnings.

The ‘fundamental premise of inclusion has always been humanist’ in orientation (Naraian, 2020:1). Schools are encouraged to celebrate ‘a common humanity’ which privileges the human traits of thought, capacity and sense-making (Naraian, 2020:1). They are organised ‘around a particular kind of learner’, ie. those who can be self-sufficient and independent (Goodley, 2021:123). In the neoliberal world we live in, we are all encouraged to become an ‘I’, a ‘bounded’ and ‘self-serving’ individual who is ‘never in need of others’ (Goodley & Lawthom, 2019:237). This is evident in the school curriculum, and within the four Preparation for Adulthood outcomes for pupils with SEND, which are ‘bound to the normative expectations of adulthood’ (Hodkinson & Burch, 2019:166). However, this rhetoric of independence and individuality inevitably results in the construction of some pupils as outsiders. The onus is placed on students and their families to make inclusion work, to demonstrate that they ‘warrant a program of inclusion’ (Naraian, 2020:2). Parents are required to demonstrate their child’s capabilities and affirm their ‘humanness’ (Naraian, 2020:4) to assert their child’s rights to education provision, whilst simultaneously needing to attest to their unique needs that set them apart to secure the additional provision they require to be included.

To move beyond existing understandings about the role of mothers and the inclusion of their children in education, we need more expansive understandings of both inclusion and mothers of disabled children that recognise their becoming and entanglement with both human and non-human entities. Therefore, instead of remaining bound to methods that are based on humanist understandings, it is necessary to attend to materiality, embodiment and affect, recognising that individual actors will ‘take form differently at different times’ in an assemblage of ‘co-evolving entities, whose relations are not stable’ (Naraian, 2023:193). The assumptions researchers hold and the ‘cuts’ that are made in ‘boundary-making practices’ will direct the outcome of research (Naraian, 2023:194,196). To produce something different, it is necessary to start with different assumptions and not rely on humanist understandings of education or inclusion, or research methodologies, as discussed above. Although some researchers have started to design innovative and creative research approaches that are commensurate with the poststructural or posthuman theories they draw on, these have primarily been in relation to school pupils (eg. Ovington, 2019; Van de Putte et al., 2020) or teachers (eg. McKay et al., 2014; Albin-Clark, 2019; Sidebottom, 2021; Naseer, 2023) rather than mothers and inclusive education.

The shift towards a process relational ontology and subjectivity as becoming, is not yet widely evident in shaping empirical research being undertaken with mothers of disabled children. There are recent exceptions to this, for instance Smith (2021), who explored how children with special educational needs and their parents can be understood relationally beyond current dominant neoliberal-ableist ideologies and Runswick-Cole et al. (2024) who designed a diffractive analysis bringing together themes from workshop discussions and a film, to theoretically explore discourses about ‘mad’ mothers in education. The use of non-traditional research approaches with mothers of disabled children remains in its infancy, and this inquiry provides a further contribution to these emerging approaches by its engagement in ‘thinking otherwise’ (Rodríguez-Dorans et al., 2021:5) about how to undertake research with mothers of disabled children about their experiences of the SEND system and education.

1.1.3 Putting theory to work to generate something additional and new

As St. Pierre (2023:30) describes, ‘the immanent onto-epistemology of poststructuralism does not allow one to think any preexisting, given, research methodology.’ Instead, it is necessary to think and live with the philosophical concepts, to invent something new. This inquiry sets out to approach inclusion within such a framework of relationality and connectivity, to explore the assemblages within which mothers of disabled children and pupils labelled with SEND are entangled and how these impact on the decisions they make. Adopting a pluralistic approach, to embrace the ‘multifaceted nature of disability in education’ (Ktenidis et al., 2022:105), I engage with theory to challenge taken-for-granted understandings about the role of mothers of disabled children in education. By drawing attention to relationality, entanglement and becoming, new spaces and new modes of being and becoming in both education and research emerge that are not based on exclusionary criteria of ability, cognition, autonomy and independence (Ktenidis et al., 2022). Adopting this orientation can help 'dismantle the rigid boundaries' that position some humans as less than, by offering a 'site of infinite possibility' that might produce new meanings of difference (Naraian, 2020:5-6).

Approaching the inquiry this way requires a shift from thinking about individual agency and capacity, to recognise how mothers are constantly becoming with/alongside each other and the environment within which they are living (Naraian, 2020). Rather than relying on an empiricist or social constructionist logic to explain inclusion, I understand meaning and matter as 'entangled within an "onto-epistemology" where all entities co-exist in a relational materiality' (Naraian, 2020:7). This relational ontology recognises inclusion as a material-discursive arrangement 'of bodies and objects that are co-constituted in their intra-action with each other' (Naraian, 2020:8). What comes to matter cannot be predicted in advance, and inclusion can 'assume a different character at different times and different places' (Naraian, 2020:8). Difference is not something situated within individual pupils but emerges in an active and ongoing process within 'the web of entanglements that mark inclusion in any setting' (Naraian, 2020:16). This is a distinct shift away from the deficit approaches to disability that still underpins SEND educational policy, practice and much SEND related research, towards something new and more inclusive of all.

1.2 Research approach

This research inquiry introduces an innovative approach to undertaking inquiry with mothers of disabled children by using conversation *as* research (Bojesen, 2020, emphasis added). This is not another way of describing a semi-structured interview or focus group. Conversation has not been utilised to generate data or voice that can be put into themes that are subsequently discussed. Rather, as I go on to explain in Chapter Six, conversation as research draws on Blanchot's *Infinite Conversation* (1993), which prioritises the movement of thought within conversation, rather than the words that are said. The affective encounters, where knowledge emerges 'in-between' in conversation, cannot be domesticated into measurable and accountable representations or a traditional thematic analysis. This approach to inquiry privileges '"withness" thinking and active ways of "being with" over "aboutness"' (Salter, 2021:386). Within this research, I embraced a 'mode of thinking which educates through interrupting oneself by means of conversation' (Bojesen, 2020:121). I was able to learn 'through being in research' as my own experiences became entangled with those of the mothers I was in conversation with (Salter, 2021:385). As Deleuze and Parnet (1977:2) describe, in this way conversation is 'simply the outline of a becoming'.

1.3 Introducing the mothers who engaged in this inquiry

Over a period of twelve months, I engaged in conversation with seven mothers of children who have Down syndrome living in England[3], about their understandings and experiences of

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[3] Therefore, the research refers specifically to English education policy, practice, and the wider landscape.

educational inclusion and exclusion. I am incredibly grateful to these mothers for generously giving up their time to take part in this inquiry and to welcome me into their lives.

Participant (pseudonym)[4]	Child's name (pseudonym)	Location	Stage of education	Any additional information
Anne	James	North England	Secondary. Split placement.	4 days special school, 1 day mainstream.
Emily	Ethan	North England	Final stages mainstream primary.	Single mother. Going through SENDIST tribunal.
George	Ezra	South England	Final stages mainstream primary.	Single mother.
Sita	Kiran	South England	Mainstream primary, moved into Junior school during the inquiry.	Military family, from South Asia.
Faith	Brave	London	Mainstream primary.	Latino. English not first language.
Jayne	Zebedee	South England	Reception year mainstream school.	Attending private school.
Clare	Thomas	South England	Final stages mainstream primary.	Going through SENDIST tribunal.

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[4] I discuss the use of pseudonyms further in Chapter Seven

Although diversity of participants was not a specific recruitment aim, the mothers engaged in this inquiry were a diverse group, as shown above.

I do not adopt an intersectional or identity based approach within this inquiry, one that would foreground identity positions such as race, class, sex or religion within this thesis. I recognise that, as Goodley (2023:168) describes, people with learning disabilities 'live deeply intersectional lives; cutting across gender, age, class, sexuality, race and place'. I also understand that learning disability and these other identities can be seen to 'exist together and in tension with one another' (Goodley, 2023:169, original emphasis). These intersections are important to understand and explore. However, this is not the orientation or focus of this doctoral inquiry.

I recognise that identity categories can be used as a powerful tool for political transformation through representational politics, however I am also concerned at how they can produce individuals as 'Other' based on individual attributes (Puar, 2011). I am also concerned that identity based political action can be seen to pit some identities against others in ways that reinforce binaries and reify exclusions (Puar, 2017). Furthermore, an identity based approach can also put the burden on theorists and activists who claim to hold specific identity categories, suggesting that they are solely responsible for bringing about change (Puar, 2017), rather than a recognition that transformation is everybody's responsibility.

Watermeyer & Swartz (2023:363) draw specific attention to how the adoption of an intersectional approach, which foregrounds the complex interaction of social positionings, can serve to 'conceal and deny disability disadvantage, rather than interrogate it'. They argue that disability can be overlooked and possibly is not even mentioned at all. I have noticed that when scholars, for example Braidotti (2022) list identity categories to take notice of, disability is rarely included in the list. Watermeyer & Swartz describe a 'selective intersectionality' where some questions of exclusion are more talked about than others, for example, they state 'though nowadays it would not be acceptable to discuss intersectionality in South Africa without mentioning LGBTQIA+ issues, it is still possible to do so without mentioning disability' (Watermeyer & Swartz, 2023:365). Davis (2002:89) argues that identity politics is unable to 'include disability under its tent' in any way 'other than with second-class status'. He suggests that disability 'is still routinely ignored, marginalized, or patronized by the very people most active in identity politics' and suggests that other identity groups are reluctant to cede 'their place of priority' as this would place their identity further down in the 'line of significance' (Davis, 2002:101). He suggests instead that all forms of oppression 'should walk, or wheel, side by side' (Davis, 2002:157), to accept plurality whilst without coming up with a 'fairy tale about empowerment, multiple voices, liberatory discourse, and so on that belies the difficult work of cultural-political practice' (Davis, 2002:101).

Later in this thesis[5] I discuss how my ethical approach is underpinned by Levinas's ethics of subjectivity, which as Biesta (2013:21) describes 'is not a matter of identity', which can lead

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[5] See Chapter Seven

to an ‘instrumental rather than an ethical relation to the other’. Biesta (2013:21) suggests that when we ‘use identity to articulate our uniqueness, we focus on ways in which I am different to the other’. Instead, Levinas suggests a subjectivity as ‘event’ in which we are singled out to respond to the other (Biesta, 2013:23). Puar (2011:7) similarly suggests that when drawing on poststructuralist and posthumanist framings, as I do within this inquiry, that identity categories ‘are considered events, actions, and encounters between bodies, rather than simply entities and attributes of subjects’. Instead of foregrounding identity categories, this inquiry and its analysis emphasises subjectivity as endless becomings, as multiple and in flux, through which it becomes possible to highlight the shifting assemblages of power (Puar, 2011; Puar 2017). Instead of using identity to indicate ‘locations of power’ where bodies and experiences are forced into identity categories, I am engaging in a ‘post-identitarian’ nomadic politics (Braidotti, 2019:182) in which the emphasis turns to process, encounters, events and relations (Puar, 2011). As Braidotti (2019:182) describes, this is not ‘a way of despising or dismissing identity’ but instead is a ‘moving beyond’.

It is also important to note, however, that by utilising this approach I am not suggesting that everyone is equal. I recognise that the ‘human’ is a ‘normative category that indexes access to privileges and entitlements’ and that there are ‘structural distinctions and inequalities among different categories of humans’ (Braidotti, 2020:466). It is necessary to recognise the ‘minoritarian subjects’ who are seen as ‘less-than’ or excluded (Braidotti, 2020:466) but to recognise how these come to being within webs of ever-shifting relations. Also, I emphasise in this thesis how ‘the strength of minoritarian subjects consists in their capacity to carry out alternative modes of becoming and transversal relations that break up segregational patterns' (Braidotti, 2019b:49). Therefore, as Braidotti (2020) describes, it is necessary to recognise how there might be 'materially embedded differences in location that separate us' but that we are all connected and 'in this together'.

This inquiry was open to all parent carers of children with Down syndrome[6], however all the parents who took part were mothers, and all their children were boys. Most research about parenting disabled children focusses on 'mothers as research subjects' (Knight, 2013:662). In their review of the literature relating to parents' experiences of raising a disabled child, Green et al. (2013) describe how mothers are clearly overrepresented in the body of literature that they reviewed, with far more mothers than fathers participating in interviews. There are specific research inquiries that explicitly focus on other carer roles who may experience their role in a different way to mothers, for instance fathers (see Davys et al., 2017) or grandparents (see Neely-Barnes & Dia, 2008). As Ryan & Runswick-Cole (2009) argue, the focus on mothers in research is not designed to undermine the roles of other carers, rather it recognises that in most families mothers are far more likely to take on the primary caring role for their disabled child.

1.4 Research questions

This inquiry explores the following questions:

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[6] See Chapter Seven for a discussion about the recruitment criteria. The use of Down syndrome as the criteria was a pragmatic choice but not an unproblematic one.

- How can the experiences of exclusion that mothers of disabled children encounter add to current understandings of inclusion in education?
- How do mothers of disabled children engage with dominant narratives, statutory processes, and everyday education practice within the SEND system?
- How are the decisions and actions that mothers of disabled children take about their child's education shaped by the past, present or future?

1.5 Thesis structure

Following this brief introductory chapter, **Chapter Two** introduces the theoretical underpinnings for this inquiry. I explain how I draw on philosophical theories that neither position some humans as 'less-than' human nor rely on deficit thinking to underpin this inquiry. In **Chapter Three**, I set out my approach to writing this thesis, and how this also aligns with the philosophical approaches underpinning the inquiry. **Chapter Four** discusses how it is impossible to separate myself – as a mother – from this inquiry. I describe how my experiences as a mother and research participant shaped the research approach.

In **Chapter Five** I describe the evolving SEND policy context and wider educational terrain, before discussing the impacts of the COVID-19 pandemic and a SEND tribunal appeal on this inquiry. **Chapter Six** introduces 'conversation as research', including a discussion about the qualities of conversation. In **Chapter Seven** I discuss the ethical and practical aspects of the inquiry, before moving into **Chapter Eight** where I discuss how creative research methods are employed within both analysis and dissemination. These chapters, which describe the inquiry that has been undertaken, are then followed by three substantive chapters, or ‘threads’, set out in **Chapters Nine, Ten and Eleven**, which have been produced through the intra-action of reading theory, engaging in conversations with the mothers and my own ongoing experiences as a mother of a disabled child/young person navigating the education system.

These threads do not represent conventional research ‘findings’. They do not closely represent the conversations that took place, nor do they highlight major themes that emerged only from the conversations. Rather the threads are theoretical discussions that came into being through the thinking and writing of this thesis. Whereas conventional research relies on the idea that data can be collected, analysed and fixed into categories, following which the findings are discussed, the approach in this inquiry, based on Deleuze & Guattari’s immanent materialism, moves ‘beyond subject-centred accounts’ and instead is a ‘thinking with and through writing text’ (Hanley, 2019:422). The threads therefore offer a tentative and uncertain ‘possibility space’ (Hanley, 2019:421) to disturb and disrupt existing understandings of concepts and dominant narratives.

Each thread starts with a theoretically informed critical discussion exploring current understandings, followed by an alternative framing that provides opportunities for thinking differently. **Chapter Nine** offers challenge to the current narratives relating to mothers of disabled children, offering an alternative approach through the employment of ‘disability affordances’. This thread initially came into being to respond to Goodley’s provocation which suggests mothers should be recognised in their becoming rather than stable identity categories. **Chapter Ten** explores the materiality of documentation, which I have termed ‘documateriality’. The focus of this thread initially emerged from a comment made by one of the mothers about the pile of paperwork on her desk and one mother’s affective engagement with a home-school diary. **Chapter Eleven** challenges the close conceptual relationship between inclusion and belonging that, as previously mentioned, is a persistent theme within research about inclusion. Drawing on notions of Garland-Thomson’s misfitting (2011), this thread explores how the desire to belong is potentially leading to more mothers choosing specialist education settings.

The three threads and the inquiry are pulled together in the final chapter of the thesis, **Chapter Twelve**. Although this chapter might traditionally be presented as a Conclusion chapter, I resist the idea that this inquiry has produced neat conclusions and instead suggest new avenues for exploration that have emerged from this doctoral study.

2. THE THEORETICAL UNDERPINNING

From the outset I wanted this research to be recognised as inclusive. Yet a significant conundrum stood before me: how to design and undertake a research inquiry that is inclusive, when the very concepts of 'inclusion' and 'inclusive education' are also explored within the inquiry. Although there might not be a clear consensus on what it means to 'be inclusive', I decided that a positive step at the outset was to employ a capacious and inclusive philosophical approach that would underpin all aspects of the research. I describe below how this inquiry relies on theoretical approaches that do not deny the humanity of learning-disabled people - including my daughter.

2.1 Inclusive philosophies

> Not all of us can say, with any degree of certainty, that we have always been human, or that we are only that. Some of us are not even considered fully human now, let alone at previous moments of Western social, political and scientific history (Braidotti, 2013:1).

When I returned to study in 2014, I found that drawing on philosophical theories to consider issues about education and inclusion allowed me distance from my home life and first-hand experiences. However, the more I studied the more I found that my relationship with my daughter had a profound impact on my engagement with theory. I came to recognise that learning-disabled people will fall short of the required standards of the ideal rational, autonomous, able-bodied/minded citizen described within humanist philosophies. For example, as Dryden (2023:158,161) describes, Kant considers individuals who lack cognitive ability have an ‘absence of soul’, that they do not have potential to develop as their naturalised biological deficit situates them outside of humanity and therefore the project of the Enlightenment. I realised that if I wanted to undertake philosophical inquiry, I needed to engage with philosophies that could ‘make room’ for people like my daughter (Kittay, 2019:xix), philosophies that would recognise her humanity, her value and her worth.

This doctoral inquiry is underpinned by Deleuze & Guattari’s immanent materialist ontology and new materialist feminisms. Deleuze & Guattari’s theories incorporate insights from the poststructuralist ‘linguistic turn’ but also recognise the importance of the material world (Fox & Alldred, 2017). Fox & Alldred (2015:401) describe how a new materialist ontology:

> shifts from conceptions of objects and bodies as occupying distinct and delimited spaces, and instead sees human bodies and all other material, social and abstract entities as relational, having no ontological status or integrity other than that produced through their relationship to other similarly contingent and ephemeral bodies, things and ideas.

Materialities ‘gain substance and shape’ as they are drawn into ‘assemblages’ which develop around actions and events (Fox & Alldred, 2017:17). Assemblages are held together by ‘the capacities of assembled relations to affect or be affected’ where ‘*affect,* is a “becoming”’ (Fox & Alldred, 2017:18). Accordingly, this ontology moves social inquiry away from the binary of either ‘realism’ or ‘constructivism’ instead recognising the importance of the ‘material-cultural’, movement and the ‘in-between’ (Fox & Alldred, 2017:20).

As well as drawing on Deleuze & Guattari's body of work, I also engage with new materialist feminisms and critical posthuman theories, for instance the work of Karen Barad and Rosi Braidotti. Using these theories moves inquiry 'beyond a critical deconstruction and critique to alternative enactments of becoming, where power is not only seen as limiting but also as affirmative' (Bozalek & Zembylas, 2016:194). Difference is seen as 'productive' and matter is 'vital and vibrant' as it is '"mutually constituted" with the discursive' (Bozalek & Zembylas, 2016:194). The traditional notion of the human emerging from the Enlightenment led to 'reiterative formulations of symbolic "others", which have functioned as markers of the shifting borders of who and what would be considered "human"' (Ferrando, 2019:24). Posthumanism developed 'out of the "margins"' of a 'centralized human subject', recognising and emphasising the 'human as a process' rather than a given subjectivity 'inherently characterised by differences and shifting identities' (Ferrando, 2019:25). Instead of positioning humans on a hierarchical scale, this approach recognises the plurality of human experience' (Ferrando, 2019:54), and therefore offers a more expansive understanding of what it means to be human. As Braidotti (2013:195) describes:

> I see the posthuman turn as an amazing opportunity to decide together what and who we are capable of becoming and a unique opportunity for humanity to re-invent itself affirmatively, through creativity and empowering ethical relations and not only negatively, through vulnerability and fear. It is a chance to identify opportunities of resistance and empowerment on a planetary scale.

It is important to note, however, that it is my intention is to retain the human subject whilst also drawing on posthuman theories (Andersson, 2022). I want to centre both mothers and learning disabled people in my thinking.

Posthuman theory attempts to decentre the human subject and place greater emphasis on non-human and material objects and relations. Whilst recognising the importance of incorporating non-human entities into this inquiry, I do so whilst being aware of how decentre-ing the human can leave the category of 'human' unquestioned. There is a danger, as Carlson (2023:61) describes, that by embracing posthuman theories that move '*beyond* "the human"' we 'inadvertently contribute to and perpetuate other forms of dehumanization for those whose humanity is still in question' (original emphasis). Further, Andersson (2022:298) describes how the urge to 'dissolve the modernist legacy that posits a narrow and transcendental notion of a human' can potentially leave problematic conceptions of what it means to be human intact. Therefore, my aim is to draw on philosophical posthumanism as a theoretical underpinning that challenges traditional humanist philosophies based on the Cartesian mind/body split that can lead to the exclusion of learning-disabled people, instead providing more capacious visions of what it means to be human (Carlson, 2023). This is important because, as Carlson (2023:58) describes:

> if we are to prevent disability dehumanization, it is imperative that we keep the humanness of people with ID in the foreground. This involves challenging and resisting discourses, practices, and policies that animalize disabled people and that deny that they are fellow human beings in other ways.

Furthermore, whilst I recognise the value in these theories when seeking to approach the difficult and multi-faceted problem of inclusion, I also recognise that recognition of entanglement 'is not enough in itself' (Giraud, 2019:7). Giraud (2019:2) describes how relational approaches can 'make it difficult to determine where culpability for particular situations really lie, let alone offer a sense of how to meet any ethical responsibilities emerging from these situations'. The complexity and entanglements emerging from a relational ontology can obscure who 'bears the greatest burden of these relations' and can lead to inaction (Giraud, 2019:4) unless it can find a way to ‘create room’ for responsibilities and obligations to emerge (Giraud, 2019:20). Giraud (2019:4) argues therefore, that alongside these relational approaches, it is therefore necessary to make ‘exclusions visible’ and to find ways to act. Exclusions can play a ‘constitutive role in materializing particular realities at the expense of others’ (Giraud, 2019:20). By paying attention to exclusion, it becomes possible to imagine some of the alternatives realities that instead could have been produced (Giraud, 2019). How things could have become otherwise. Therefore, I will be using the philosophical theories within this thesis to draw attention to such exclusions, and to use this as a springboard from which alternative approaches can be imagined.

Philosophy and disability can often be seen as uncomfortable bedfellows, as the embodied, active lives and perspectives of disabled people – especially learning-disabled people - are frequently absent within the academic discipline of philosophy (Carlson, 2021:74). As Veck & Hall (2018:1084) describe, for research to be inclusive it is necessary that those who are engaged in the research inquiry are ‘methodologically includable’. However, both learning-disabled people and intellectual disability as an area of focus are generally excluded from the ‘philosopher’s house’ (Carlson, 2021:72). There is an under-representation of disabled philosophers (Tremain, 2017) and it is even less likely that disabled scholars engaging in philosophy have learning disabilities due to the underlying assumption that ‘philosophy relies upon a certain kind of cognitive ability, a certain capacity for reasoning’, which paints a picture of who can fit within the field (Flowers, 2022:93-4).

Intellectual disability tends to be recognised as an ‘unproblematic’ and ‘self-evident’ category of individuals ‘about whom philosophical analogies and comparisons can be made’ (Carlson, 2010:11). Intellectually disabled people are only ‘brought into the philosophical fold’ as profoundly and radical ‘others’ who depart from ‘the normal’ (Carlson, 2010:4), as a life not worth living, rather than being recognised ‘as knowing subjects in their own right’ (Carlson, 2010:15). Yet, as Carlson & Kittay (2010:2) argue, although people who have cognitive disabilities are outliers or exceptions with the ‘standard philosophical conception of the person’, intellectual/learning disability is a feature of the human condition that touches the lives of all and should be taken seriously. I am therefore committed to ensuring that my engagement with philosophy within this inquiry does not suggest disabled people are less than, defective or a problem to be solved (Tremain, 2017). Instead, my aim is to use philosophical inquiry to disrupt such deficit and exclusionary thinking.

2.2 Resisting deficit thinking

Whilst recognising that ‘mothering a disabled child is fundamentally a different experience to mothering a non-disabled child and that this difference should be acknowledged’ (Ryan & Runswick-Cole, 2008:203), I am not suggesting that bringing up a disabled child is ‘painful’ nor am I implying that having a disabled child is a ‘terrible thing’ (Ryan & Runswick-Cole, 2008:203). There is a substantial amount of research literature that couches the experiences of parents of disabled children ‘in terms of grief, loss or denial’ (Ryan & Runswick-Cole, 2008:201). As Lalvani (2019:4) describes, such assumptions about the wholly negative nature of parenting a disabled child ‘are upheld in professional discourses that frame the birth of a child with a disability as a “tragedy” or profound loss’. Accordingly, parents of disabled children are often described as ‘saints’ for raising children with disabilities, as ‘special’ mothers who are ‘blessed’, or lucky to be chosen recipients of a ‘special’ child (Lalvani, 2019; Smith & Smith, 2021). Either way, the birth or diagnosis of a disabled child sets the family apart, even though many aspects of their family lives might be similar to ‘typical’ families’ lives (Patching & Watson, 1993). There is a risk of ‘exoticizing the experiences of mothers of disabled children’ in a way that will marginalise them further (Ryan & Runswick-Cole, 2008:203), something I hope to avoid in this inquiry by avoiding such tropes and deficit thinking.

The social model of disability, emerging in the mid-1970s in the UK, offers an alternative way of thinking about disability that is not based on a medical model or deficit thinking. Theorists who support this model argue that disabled people are not disabled by their impairments but by barriers they face in society. The approach is 'situated in the direct experience and understanding' of disabled people themselves (Terzi, 2004:143). It evolved as a form of disabled people’s activism that vehemently opposed the hegemonic medical model of disability that had long dominated disability policy and service provision (Oliver, 2004). However, the social model was never intended to be an ‘all-encompassing framework within which everything that happens to disabled people could be understood or explained’ (Oliver, 2013:1024). Rather, it was meant to be a vehicle for ‘developing a collective disability consciousness’ to strengthen the disabled people’s movement, and as ‘a tool to improve people’s lives’ through empowerment (Oliver, 2013:1024-5). The intention was to move away from perceiving disabled people as ‘tragic victims’ (Oliver, 2013:1026).

Unfortunately, as McClimens (2003) and Bérubé (2010) both discuss, the theoretical space generated by the social model of disability does not necessarily include people with learning disabilities, due to its focus on disability being the result of built environments and social relationships. Rather than understanding disability as socially constructed, McClimens (2003:37) argues it is important to recognise how 'there are some things actually "out there" that individuals must deal with'. The presence and situation of learning-disabled people forces a reconsideration of the simplistic medical/deficit vs social model debate. A common critique is that the social model was conceived and developed by physically disabled people and can often be seen to fail to have an impact on the lives of learning-disabled people as they are excluded from the disability movement (McClimens, 2003; Chappell et al., 2001). Bérubé (2010:103) citing Deleuze suggests that 'we are still too accustomed to think in terms of the ''indignity of speaking for others"' and that 'to meet the challenge of cognitive disability' in philosophy and academia, then 'we will need to think harder about the limits of the social model - and we will need to think more seriously about the roles of guardians'. I recognise the importance of the complex advocacy role that mothers of learning-disabled children are required to occupy, especially in relation to their child's education, which is the focus of this inquiry.

It is because of my relationship with my daughter, that I have come to recognise the importance of theories that incorporate the material, the lived body, and embodied experiences. Therefore, whilst I understand the significance of the social model of disability as a mechanism that supports disabled people's activism, I also recognise there is greater complexity for some learning-disabled people. I take the position that disability can be experienced in and through the body as well as when facing societal barriers to participation, including cultural and societal narratives and structures that constitute how impairment is understood and experienced. This recognition of the importance of acknowledging the embodied nature of disability has also influenced the philosophical approaches I draw on when undertaking this inquiry.

Whilst this thesis draws attention to some of the challenges that parents face when advocating for their child's education and inclusion, as mentioned above my intention is to approach this inquiry in a way that is not underpinned by a 'position of negativity' as described by Ryan & Runswick-Cole, (2008:203). Accordingly, I respond to Goodley (1999:26) who states that disability focused research should 'aim to work from a capacity rather than deficit perspective, focusing on what people can do in spite of lives that are filled with disablement'. I reject hegemonic framings of disability that 'individualise, pathologise, medicalise, psychologise, essentialise and depoliticise the phenomenon of disability', instead seeing disability as both 'a signifier of inequity and the promise of something new and affirmative' (Goodley et al., 2019:973). As I discuss below, I bring together a rich tapestry of poststructural, feminist new materialist and posthuman theories to underpin this inquiry, which will enable me to achieve these aims. These theories are brought together with conversations with mothers of disabled children, to explore how mothers experience and navigate the discourses and structures that influence the processes of parenting a disabled child in relation to their child's education and inclusion. As an important part of this, this thesis will specifically set out to explore how mothers of disabled children 'can be seen as architects of change and progress by caring and acting on behalf of their children' (Bosteels et al., 2012:984), to envisage different ways we might be able to think about both the role of mothers and the inclusion of disabled children in education.

2.3 Developing a research praxis that is inclusive

'Inclusion' remains an elusive and contested concept (Webster, 2022) and there are a variety of views as to what it means to be 'inclusive'. I therefore am attempting to be inclusive in research that explores inclusion, without being able to clearly define 'inclusion' before I start. There are several theories and definitions of inclusion, often posited in contradiction to one another (Simplican & Leader, 2015). Allan & Slee (2008:1) describe the field of inclusive education as both 'troubled and troubling', a field that is populated with 'deeply entrenched positions' that result in 'a series of frequently emotive and highly charged contests'. There has been an 'awkward blending of the discourses of special and inclusive education' (Allan & Slee, 2019:2), which can add complexity to this labyrinthine field. It is therefore necessary, as a novice researcher, to understand how these ongoing tensions and controversies are 'woven into the very fabric of the field' (Apple, 2008:vii) and to navigate the terrain carefully.

I need to avoid the pitfall that Allan (2008:43) describes, where researchers studying inclusion 'may end up undertaking research which is highly exclusionary, but which they do not recognise as such'. The field of special education and inclusion 'hosts a broad assembly of constituents and conceptual frameworks' (Allan & Slee, 2019:2) that emerged from a time when some disabled children were seen as ineducable and others were educated in segregated provision. As Byrne (2022:301-2) describes, there have been numerous attempts to ‘establish the boundaries of inclusion’ and the ‘inclusion umbrella has become so broad and all encompassing, that it risks becoming a new way to describe and legitimise age old norms of mere integration and/or segregation within mainstream settings’ (Byrne, 2022:301-2). Allan & Slee (2019:2) describe how there has been a ‘steady erosion of language through an awkward blending of the discourses of special and inclusive education’ where ‘Special Educational Needs’ has become ubiquitous and the default language when discussing disabled children in education (Allan & Slee, 2019:5). Research relating to this category might appear to be inclusive on the surface, but it can still rely on an understanding of the child as deficient or lacking or philosophies that might exclude them outside of conceptions of humanity. It becomes possible to undertake research that is based on exclusionary principles without realising, despite an original intention to undertake inclusive education research (Allan & Slee, 2008). Therefore, it was important that this research was designed in a way that resists the ‘formidable special education – positivistic – paradigm’ and that it considered issues relating to values and issues of power at each stage of the process (Allan, 2008:44). The inquiry recognises how family lives are embedded in ‘systemic, institutional practices’ which can have power over them and can shape the choices that they make (de Schauwer et al., 2020:5). Discursive, structural and material practices can make boundaries that shape the space in which we can inhabit, determine what behaviours are possible, and therefore what life directions we can follow and what norms and values come to matter (de Schauwer et al., 2020). The findings suggest that resistances through affirmative practices can lead to greater inclusion.

2.4 Subjectivity as becoming

This inquiry is based on a philosophical and methodological approach that recognises subjectivity as becoming in a world that is ‘fundamentally multiple, dynamic, fluid and co-constituted by entangled material and discursive forces’ (Strom et al., 2018:xx). Therefore, both my researcher and maternal subjectivity are entangled and relationally becoming, within the evolving research approach, the Academy into which I am being inducted, the disciplinary logics within which I am engaging, and the emerging relationships with parents taking part in the research inquiry (Warfield, 2019:153). This approach sits in contrast with traditional approaches to research where there is an expectation of an ‘I’ – the ‘I’ who is writing, learning and thinking, the ‘I’ who is ‘presumed to be knowable, intact and separate’, the ‘I’ who can predict which way the inquiry will develop and how conversations might flow (Naraian & Gabel, 2022:2).

Within the humanist legacy, subjectivity is equated with ‘consciousness, universal rationality, and self-regulating ethical behaviour’ (Braidotti, 2013:15). Braidotti (2013a) describes how the universal model for what it means to be human within Eurocentric humanism is based on the universal classical ideal of Vitruvian man[7]. She describes how there is:

> an ideal of bodily perfection which doubles up as a set of mental, discursive and spiritual values. That iconic image is the emblem of Humanism as a doctrine that combines the biological, discursive and moral expansion of human capabilities into an idea of teleologically ordained, rational progress (Braidotti, 2013a:2).

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[7] The Vitruvian Man is a drawing by Leonardo da Vinci. The significance of the image of Vitruvian Man lies in its representation of the universal human ideal. The image is perfectly symmetrical and reflects classical notions of beauty and perfection.

This can lead to some humans being seen as ‘less than human or inhuman’ (Goodley et al., 2014:343). As Braidotti (2013:26) describes, the universal ideal relies on ‘a systematized standard of recognizability – of Sameness – by which all others can be assessed, regulated and allotted’. Disabled people ‘become known in terms of what they are not’ as they fail to match up to the humanist ideal (Goodley et al., 2014:343). This has implications for inclusive education research, as traditional humanist research approaches position ‘researchers outside the phenomenon they are investigating, rather than entangled with the way it comes to *be’* (Naraian, 2020:3, original emphasis).

An onto-epistomological approach that displaces the humanist ‘I’ shifts thinking away from ‘bounded individuals’ towards ‘connected, shifting multiplicities’ and the recognition that we are all part of a ‘larger multiplicity of human-and’ (Strom et al., 2018:xx). As Martin (2018:21) describes, this conceptual and methodological shift recognises both researchers and participants as ‘always enmeshed as a member of the research assemblage’ instead of the normative construction of individual researchers, participants and research. This conceptual shift is employed in this inquiry to think differently about mothers of disabled children, recognising them instead as becoming in assemblage (Goodley et al., 2014:352). This ‘affirmative positionality’ offers an alternative approach to the ‘oppressive nature of humanism’, based on a recognition of the self ‘as an extended, distributed, interconnected and relational entity “embodied and embedded”’ (Goodley et al., 2014:343-6).

Therefore, this inquiry is based on an ‘onto-epistomology’ that is not based on a disembodied rational individual subject, rather it recognises that I am ‘merely one part of an entangled material-discursive formation collectively producing the “results” of the inquiry’ (Strom et al., 2018:xx). There is no ‘pre-constituted “I”’ that can unambiguously be identified by social identity markers, and it is therefore impossible to claim mothers ‘*have* a subjectivity which I then write *about*’ (Naraian & Gabel, 2022:5, original emphasis). As this inquiry recognises subjectivity as relational and becoming, it is not designed to ‘capture’ experience through words or images. Instead, the intention is to ‘produce the conditions for encountering the world differently’ (Naraian & Gabel, 2022:8).

As I will go on to discuss, as researcher I am entangled in the conversations that I take part in, the texts that I read, texts that are ‘always already in conversation with other texts and texts that have never been written’ (Murris & Bozalek, cited in Naraian & Gabel, 2022:8), and in other encounters and events as a mother of a disabled child. Everything effects how I experience everything else, and I am just ‘one of many entangled material and non-material agencies with-in arrangements that collectively constitute a phenomenon’ (Naraian, 2020:7).

3. WHAT TO EXPECT FROM THIS THESIS – WRITING SOMETHING DIFFERENT

3.1 Introduction

The writing of this thesis is an attempt to ‘think-with theories *and* write-with theories’ (Kuby, 2023:36, original emphasis), to enact and embody the theoretical concepts employed, and to ‘perform the entanglement of self, philosophy, and method’ (Tesar, 2023:17). As Carlson et al. (2023:1) describe, writing ‘becomes a method of research as well as part of the research process’. Therefore, this thesis does not ‘offer an account of what happened’ and nor do I ‘represent a data set’, rather the writing itself is ‘a doing’, a ‘performance of research’ (Carlson et al., 2023:1-2). Whilst research textbooks often suggest that a traditional doctoral thesis will have an introduction, literature review, methodology/research design, results, discussion, and conclusion, this inquiry does not lend itself neatly to such a structure. This chapter explains why this thesis cannot be neatly mapped onto the traditional format and what to expect instead.

3.2 Felting philosophy and empirical research

This inquiry offers a philosophical exploration of the subjectivity of mothers of disabled children and factors that contribute to educational inclusion/exclusion. Due to the philosophical underpinnings, this inquiry also necessarily incorporates an empirical element. This is not an empirical study based on conventional humanist qualitative methodological approaches, such as researcher interviewing a participant or focus groups interviews. It does not follow a linear approach of gathering data that is subsequently analysed, interpreted, and discussed, with philosophy being reduced to a supporting role in the process. Instead, as previously discussed, this inquiry departs from the assumption that there is a 'knowing subject of humanist empiricisms' engaging within a world that 'exists separate from human beings as an objective entity that can be known in its entirety' that can be explored through empirical evidence (St. Pierre, 2016:116-7). This inquiry is underpinned by a relational and processual ontology (Braidotti, 2013b) that 'holds that entities do not ontologically pre-exist relationships, but rather that entities come into being through human and more than human relationships' (Murris & Bozalek, 2019:874). Individuals do not exist independently from others or the world we live in, rather we are in a continual process of 'becoming-with' the material-discursive world (Lenz Taguchi, 2010:39). As Barad (2007:85) states:

> We don't obtain knowledge by standing outside the world; we know because we are of the world. We are part of the world and its differential becoming.

I must therefore attend to the dynamic and fluid relations from which power emerges and through which worlds are made (Braidotti, 2013).

Prior to starting my doctoral journey, I had anticipated that this research would be a purely theoretical desk-based study drawing on Foucault[8], and maybe other 'philosophers of difference' introduced by Allan (2008). I had only engaged in 'educational philosophy' previously, an approach that is distinct from using philosophy as just one element of empirical research about education (Fulford & Hodgson, 2016:4). This is philosophy 'as research', where a philosophical exploration of educational issues 'constitutes a coherent and valuable research project in its own right' (Suissa, 2007:285). Philosophical research is

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[8] I had studied some of Foucault's works and put his theories to use for both my Undergraduate and Masters' dissertations.

‘centrally concerned with questions of meaning and value, with conceptual matters and with the coherence of ideas… quite often with some kind of struggle with ideas’ (Standish, 2010:11). Educational philosophical research does not include empirical research methods, rather it ‘proceeds through argument and use of sources’ that are read in-depth (Fulford & Hodgson, 2016:3), from which the individual researcher ‘construct[s] concepts, theories and arguments, employing logic and reasoning to resolve conceptual and normative problems’ (Golding, 2015:206).

However, as I read more theory, the more it became clear that I needed to ‘take the empirical world seriously’ (Barad, 2007:244) rather than engaging in a purely philosophical inquiry. It was clear that to approach the unresolved ‘project of inclusion’ I would need to ‘puzzle over it together’ with others Allan (2008:164). Furthermore, embracing a relational philosophical approach recognizes that ‘philosophy is enacted in the world—in the news, (social) media, policies, professional organizations, schools, relationships’ (Kuby in Tesar et al 2022:1244), it is not something that can be purely desk-bound.

Philosophical and empirical approaches to research within education are often seen as ‘two ships passing in the night’ (Barrow, 2005), as antithetical approaches that need to be ‘kept apart’ as researchers ‘choose either philosophical or empirical methods for approaching an educational problem’ with no ‘fraternising’ between the two (Golding, 2015:206). However, within this inquiry philosophy and empirical aspects are continually becoming together, enmeshed and inseparable. Instead of seeing philosophy and empirical research as distinct aspects or disciplines that either remain distinct and apart or brought together in different blends or weaves, the philosophical research inquiry and the empirical aspects of the inquiry ‘depend upon each other and are mutually constitutive’ (Lenz Taguchi, 2010:35), ie. they are in intra-action (Barad, 2007).

When drawing on poststructuralist philosophy to design a research inquiry, it requires ‘a different approach *from the beginning’* (St. Pierre, 2014:3, original emphasis). As St. Pierre (2014:9-10) describes, it is necessary to bring along the ‘entire ontology’ rather than just plucking out and using one distinct concept. There should not be a disconnect between theory and methodology, or the abandonment of underlying assumptions within ‘post’ theories to ‘insert our work into the recognizable, comfortable structure of humanist qualitative methodology’ which can lose the ‘magic of inquiry’ (St. Pierre, 2014:10-11). Rather than reducing complexity to fit a pre-existing, systematic, legitimate research process, it was therefore necessary for me to begin with ‘the epistemological and ontological commitments’ that come with the system of thought that I am engaging with (St. Pierre, 2014:10). Accordingly, philosophical theory permeates every aspect of the inquiry, as I ‘bring into being that which does not yet exist’ (Deleuze, cited in St. Pierre, 2016:122).

To be entangled ‘is not simply to be intertwined with another, as in the joining of separate entities, but to lack an independent, self-contained existence’ (Barad, 2007:ix). Within this ontology, philosophical inquiry can only be recognised as being ‘inextricably fused’ with the material and the discursive in intra-action (Barad, 2007:3). This troubles the philosophy/empirical binary that exists in many approaches to educational research, and offers an alternative approach to undertaking educational research, recognising the ‘ever-evolving entanglement of mutating co-emergence and co-composition' (Springgay, 2022:4). This challenges any suggestion that philosophical and empirical approaches to research can be mutually exclusive. It is necessary instead to acknowledge 'that practice is already and simultaneously theoretical and material, and that theory is totally dependent on experiences and fantasies of lived material practices' (Lenz Taguchi, 2010:21).

I have found the materiality of felt useful to think with and to illustrate how I conceive the relationship between philosophical and empirical aspects of this research further. As Springgay (2022:9) describes, Deleuze and Guattari call felt an 'anti-fabric' and they use it 'as a model for smooth space, space which could be defined as full of potential'. Felt is 'a nonwoven fabric composed of interlocked fibers' which has 'no warp and weft' (Springgay, 2022:8-9). When it is formed, through 'matting, fusing, condensing and pressing fibers together', the 'individual coils of wool are no longer individual but become an aggregate of the whole' in an irreversible process (Springgay, 2022:8-9). The wool fibres 'commingle' and become enmeshed, so much so that the individual fibres become indistinguishable (Springgay, 2022:9-10). Deleuze & Guattari (1987:475) describe how felt 'implies no separation of threads, no intertwining, only an entanglement of fibers'. As a result, it is, 'in principle infinite, open, and unlimited in every direction; it has neither top nor bottom nor center; it does not assign fixed and mobile elements but rather distributes a continuous variation' (Deleuze & Guattari, 1987:475-6).

I have designed an inquiry that felts together philosophical inquiry *as* research and empirical inquiry with parents of disabled children in a shift to recognising 'entangled becomings' where theoretical and empirical aspects of the research are intertwined and intra-acting with other ‘bodies, materials and artefacts in the world’ (Lenz Taguchi, 2010:24). With intra-action, everything affects everything else, ‘in a continuous process of becoming’, constituted continually by a flow of ‘force and intensities that work in both predictable and unpredictable ways’ (Lenz Taguchi, 2010:15). This awareness of ‘how everything is connected and affects everything else’ (Lenz Taguchi, 2010:39), also requires us to recognise the inseparability of the researcher from what is being researched. As Lenz Taguchi (2010:41) describes, ‘what we are, or rather, continuously become, cannot be separated from our process of knowing.’

3.3 A relational approach to ‘the literature’

There is not a standalone literature review chapter within this thesis, rather I engage critically and in-depth with a range of research and other forms of literature throughout the thesis; this is particularly evident within each of the three threads[9]. As Ribenfors (2020:232) describes, ‘an emphasis on academic voices and the omission of non-academic voices could be interpreted as echoing the expert versus lay-person hierarchy that many disabled people experience in day-to-day life’. Parents of children labelled with SEND can often be excluded and unheard in their interactions with schools (Mann et al., 2020) and believe that professionals do not value their expertise or experiences as a parent (Clarke, 2013). I wish to avoid ‘replicating entrenched power hierarchies’ based on the well-rehearsed arguments of those who are recognised as having the ‘voice of authority’ (Ribenfors, 2020:2). Therefore,

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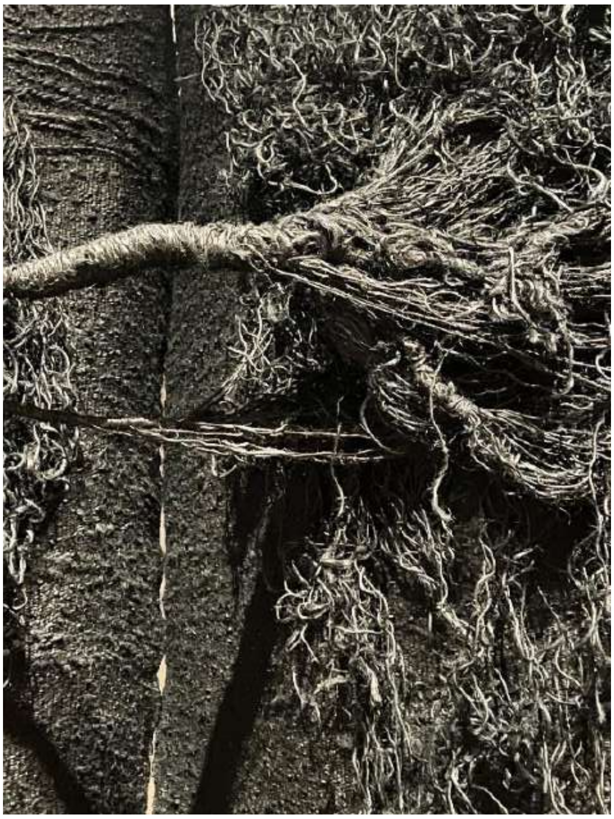
[9] Chapters Nine, Ten and Eleven.

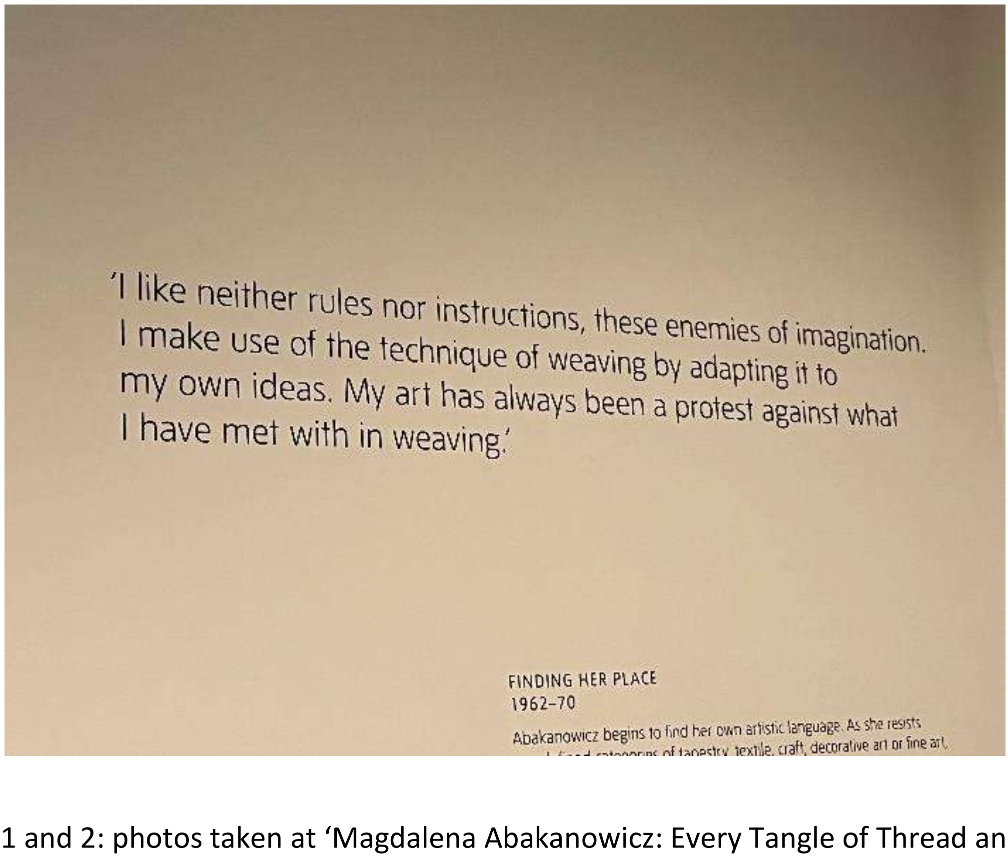
throughout this inquiry as well as exploring academic literature, I also draw on ‘real-world’ knowledges (Ribenfors, 2020:233) that are in the public domain, eg. parents’ blogs or memes, along with the year-long conversations with mothers; combined these offer ‘endless sources of insight and perspective’ to ‘think and rethink’ with (Franklin-Phipps, 2017:21).

Throughout the thesis I ‘perform’ an engagement with a broader literature in ‘a situated and embedded doing’ (Sauzet, 2021:89). I engage in a ‘close, detailed, care-full, respectful reading’ (Murris & Bozalek, 2019:879) of academic literature and bring this into relation with real-world knowledges, to make new connections and create original insights in relation to the inclusion of disabled children in education. In line with new materialist feminisms, this is an affirmative practice to create something new, rather than purely offering critique. This approach builds on existing research and real-world knowledges, as a starting point for emerging new knowledges. There will be a ‘do-ing’ of the literature rather than a review. The literature – both academic and grey literature – are brought together with the conversations that took place, and my own experiences as a mother, to produce something new.

This inquiry was not bounded to the times when sat at my desk reading or writing. Throughout my engagement in this research, I have welcomed serendipitous connections, as discussed by Van der Tuin & Pekal (2023). I have enjoyed stumbling upon either a text or an image that immediately reminds me of, or connects to, something else and attending workshops or events that are not directly related to the inquiry, but through which my thinking about inclusion moved on. Indeed, it would often be that when reading a tweet on

Twitter/X or magazine article, visiting an art exhibition, listening to feedback on a presentation made at a conference, or dealing with my own daughter’s education settings that connections might be made, or new lines of questioning might arise. I have remained alert to things I am captured or bewitched by, welcoming disruptions to my thinking or questions that puzzle me to the point of distraction (Corson & Schwitzman, 2018). Van der Tuin & Pekal (2023:48) describe how it is in such moments that I would ‘become a researcher’, when finding myself ‘conversing with a piece of scholarship, a philosophical idea, or a piece of art that needs unpacking and will lead to yet other texts or visual materials.’



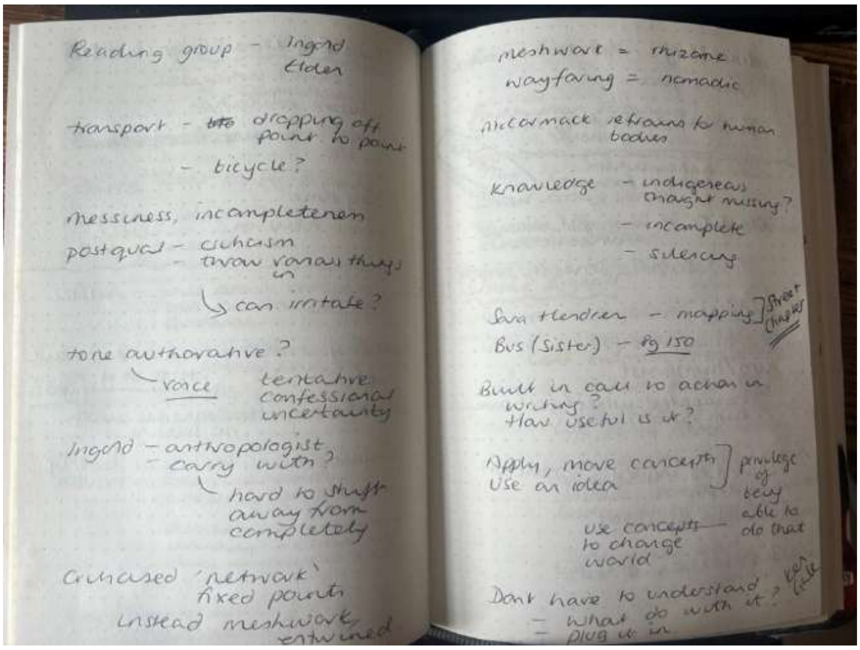


'I like neither rules nor instructions, these enemies of imagination. I make use of the technique of weaving by adapting it to my own ideas. My art has always been a protest against what I have met with in weaving.'

FINDING HER PLACE
1962–70

Abakanowicz begins to find her own artistic language. As she resists categories of tapestry, textile, craft, decorative art or fine art,

Images 1 and 2: photos taken at 'Magdalena Abakanowicz: Every Tangle of Thread and Rope', Tate Modern London 24 March 2023



Reading group - Ingold
Elden

transport - dropping off point to point
- bicycle?

messiness, incompleteness
postqual - criticism
- throw various things in
↳ can irritate?

tone authorative?
voice — tentative confessional uncertainty

Ingold - anthropologist, - carry with?
hard to shift away from completely

Criticised 'network' fixed points
instead meshwork, entwined

meshwork = rhizome
wayfaring = nomadic

McCormack refrains to human bodies

knowledge - indigenous thought missing?
- incomplete
- silencing

Sara Hendren - mapping] Street Charter
Bus (Sister) - pg 150

Built in call to action in writing?
How useful is it?

Apply, move concepts] privilege of being able to do that
Use an idea

use concepts to change world

Don't have to understand? [illegible]
— what do with it?
— plug it in

Image 3: Notes from a reading group session

Image 4: 'Mum' the witch[10].

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[10] I made her in a Halloween themed doll-making workshop run by Sam McKechnie at Batsford Books in October 2023. I was reflecting on how mothers are often demonised however they might act or dress.

During the process of this inquiry, I engaged in several reading and writing groups with fellow doctoral researchers and Early Career academics. We come together online to discuss texts, to question, to find glimmers of meaning, something relevant for our work, forwarding our collective thinking. Notes are jotted down, not attributing comments or thoughts to one person – myself or others – in this collective thinking in process, where paths and interests fold and unfold and intra-act. It is impossible to separate out the literature that 'I' have engaged with in this inquiry, because my thoughts blend and flow alongside the thoughts of others, and we are all entangled in our own multiple and ever-shifting webs of relation. All entities, encounters, entanglements 'are inseparable and blend from one into the next' (Wilson, 2008:70), as 'thousands and millions of relationships come together… from the past, from the present and from your future' (Wilson, 2008:76).

Online reading groups provide opportunities 'for us to touch and be touched by others' (Bozalek et al., 2021:844). Through our 'collaborative reading and sensemaking' (Bozalek et al., 2021:848) we were both enacting and entangled within the very philosophical approaches we were attempting to explore. As Corson & Schwitzman (2018:56) describe, there are many elements that contribute to a research inquiry that 'appear nowhere in authorship'. The knots of relationships, the seeds planted, germs of an idea and the affects we have on each other are impossible to separate or pin down. Accordingly, it is impossible to fully account for 'the ghostly spectres present and unpresent in the texts I read, write, and cite' (Carter, 2022:32), because some thoughts are so fleeting that I fail to capture them, but they may return as I read other texts, engage in conversation, or sit down to draft future iterations and performances of this research inquiry.

This inquiry relies on an understanding of knowledge as ‘relational’ (Wilson, 2008:56), where ‘relationships do not merely shape reality, they are reality’ (Wilson, 2008:7), meaning also that knowledge is not something that can be found and reviewed, but rather it is ‘produced and productive’ in the event (Daniels, 2017:105). As Murris & Bozalek (2019:878) describe:

> A relational view of reading a text assumes that the relationship is prior to the text and the reader – neither pre-exists the other. Both are articulated with and through the other, and both are affected by and affect each other as constitutive forces, leading to unpredictable and creative provocations and becomings.

I am approaching my engagement with existing literature and previous research from an understanding of ‘self’ as part of ‘an endless spiralling of connection and interaction’ (Hargraves, 2016:543) in assemblage.

Deleuze and Guattari offer an alternative to the ‘arborescent’ approach to engaging with the literature, an approach that seeks to establish foundational roots of an inquiry. They describe how the ‘tree is already the image of the world’ which leads to a ‘binary logic’ that limits the options available, whereas in nature roots ‘are taproots’ expanding within an indefinitely multiple system, grafting onto other elements, leading to infinite possibilities (Deleuze & Guattari, 1987:5). Therefore, it is necessary to ‘stop believing in trees, roots, and radicles’ (Deleuze & Guattari, 1987:15), and instead engage in multiplicities that are rhizomatic, where there are ‘only lines’ connecting one element to another (Deleuze & Guattari, 1987:8). Heterogenous elements form ‘a rhizome’, with circulating ‘intensities’ in a process of becoming (Deleuze & Guattari, 1987:10).

It is energising to think in this way, engaging with texts in ‘indeterminate and free-spirited ways driven by experimental inquiries and impulsive curiosities… as an insect might move from plant to plant in search of food and sustenance’ (Gale, 2018:3-4). What comes to matter is what the book, or literature, is processually plugged into and what sparks might fly (Gale, 2018:8). It is this process of plugging in that brings concepts to life (Gale, 2018:56). As Gale (2018:9-10) describes, rather than attempting to fix concepts in place, they need to be ‘dusted off and applied in different settings and contexts’ to produce something ‘new, experimental, processual and transmutational’ in an active process of conceptualisation. This is what I set out to do within the three substantive threads that emerge from this inquiry[11]. The literature and research that I draw on to produce this thesis is therefore visible everywhere as it is (re)produced and put to work within a multiplicity to create something new.

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[11] Chapters Nine, Ten and Eleven.


The work of caring for and supporting others is often underappreciated and under-resourced. Is that partly because it is invisible to many of us?
"We've lost the capacity to think both radically and imaginatively.
THE MORE SPACE THERE IS FOR DANCING, THE BETTER I FEEL
"MORRIS MIXED HIS PAINTS LIKE HE MIXED HIS POLLEN"
For contemporary artists, the playground is the perfect canvas on which to "open hearts" and knit communities
ALL WELCOME HERE
WIND OF CHANGE
NEW EMERGING PERSPECTIVES
EXPANDING HORIZONS
a Rebellious Act
in relation
FORCE OF CHANGING TIDES
Celebrating
"A world without walls"
listen and share
grow and learn
It's a combination of friendship
Fellowship
Solidarity
Checking in
Social
Rebuilding
Provocation
Rebalancing the field
Branch out with these solar hogweed stems
"UNDER THE GLISTENING POLISH OF THE CITY YOU HAVE THIS FRENETIC PULSE"
The act of making can mean anything
"It's a lot of colour"

3.4 Presentation of the thesis

Carlson (2023:83) asks how one might write ‘as an ontology of immanence’, as ‘a modality of writing’ that is ‘always becoming, never static’, rather than following the impulse ‘to capture, to organise, to reveal, to characterise’ that is so evident within qualitative research (Carlson, 2023:89). Within this thesis I present writing that is ‘alive and breathing’ (Lesko & McCall, 2023:61), that recognises meaning-making and knowledges as still becoming. I offer food for thought, through ‘multiple threads of reflection and inquiry’ that unfold ‘in nomadic and explorative’ ways (Ferrando, 2023:13-4). This is a ‘writing as assemblage’ where ‘the writing tries to attune to things coming into being rather than describe a system that is already set in place’ (Lesko & McCall, 2023:60-1).

This thesis is incredibly personal to me. It cannot be otherwise. I have carried my daughter’s exclusion and oppression with me every day for the past 19 years. Readers will therefore find personal reflections entangled with theoretical discussions, collage and poetry[12]. Images and found poems are inserted throughout the thesis as moments of disruption, without further explanation. As with the text, these aspects of the thesis remain open to new connections and knowledges being made by the reader. This inquiry and thesis is designed to start new conversations about mothers of disabled children and the inclusion/exclusion of disabled children from education, rather than to produce final neat conclusions.

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[12] The use of collage and poetry is discussed further in Chapter Eight.

There is no one way to read the thesis. Although in places it does follow a traditional PhD-thesis format, which might encourage a linear reading, I hope that readers will take up this invitation to engage with the thesis in a way that makes sense to them rather than it being necessary to read from beginning to end. I invite the reader to ‘think-with’ the threads, the felting of philosophy and empirical research, the entanglements and the stories that are presented within this thesis (Fairchild, 2023:140). As Bhattacharya (2023) describes, when we ‘release our work to the world’ it is no longer exclusively ours, as we cannot control how ‘reading unfolds for others’ (Bhattacharya, 2023:115). I look forward to hearing where this work lands and what differences it might make.


THE SHAPE OF THINGS TO COME
Creating
USING SPACE AS A TOOL
Mix and mismatch
infinity
it didn't matter what it was.
DYNAMIC
CONSTELLATION
EVERYTHING IS ALIVE
Taking flight
That interplay between
WHAT HAPPENED NEXT
Multiple
pluralistic, flexible and inclusive
from the get-go
EXPANDING
connection
attentive
to
AFFECT
most exciting
The process of making

3.5 Easy Read version

Academic conferences and journal articles are likely to be out of reach for most learning-disabled people. Whilst some disability studies led academic conferences might invite learning-disabled people to present about their experiences or a research inquiry they have been involved in, most academic conference presentations are likely to be difficult for learning-disabled people to both attend and fully engage with. Likewise, journal articles might be co-authored between researchers and learning-disabled people, but very few will be written in a way that learning-disabled people can easily access them (Iriarte et al., 2023). Whilst a small handful will include Easy Read (eg. Goodley & Moore, 2000; Runswick-Cole et al., 2024a), plain English versions of journal articles, or video abstracts (eg. de Haas et al., 2022), few research outputs can be accessed by learning-disabled people. Goodley & Moore (2000:873) discuss how the production of accessible research outputs is ‘not only a marginalised activity in academic contexts’ but it is also ‘rendered incredibly difficult’; however, they contend that it is no longer good enough ‘to recognise and confess the difficulties’. It is necessary to incorporate changes to research outputs that are valued by disabled people. They suggest that a reliance solely on text can be disempowering (Goodley & Moore, 2000:875) and therefore I have taken time to consider how I can address this in this inquiry.

One way to make my work accessible to a wider audience is through the production of easy read documents, which combine pictures and short sentences. The lack of plain English or accessible formats in discussions of what constitutes inclusive research ‘potentially leaves people with learning disabilities outside critical discussions on inclusive research' (Iriarte et al., 2023:208). Aspis (2022) suggests that there is no commitment from researchers to produce resources in Easy Read formats, and that it is often left to learning-disabled groups to do this work on behalf of other learning-disabled people. In response to this provocation, I undertook a ten-week PhotoSymbols training course, so that I could produce an Easy Read document to accompany this thesis that can be accessed by learning-disabled people – including my own daughter. This is an integral part of the presentation of this thesis and should not be seen as an add-on or after thought. The Easy Read version offers a further representation of this research inquiry that allows this inquiry to be accessible to learning-disabled people, not least so that they can hold me to account if I have produced work that is unintentionally exclusionary or oppressive[13]. The Easy Read version is in Appendix One.

3.6 Terminology

> We need to listen to what we say. Unless we consciously hear our own words, we are unable and unwilling to question what feelings are revealed beneath ill-considered mouthing (Corbett, 1996:3).

Words have power and words can hurt (Ferrigon, 2019). Barnes (1992) describes how language plays a large part in how people 'know' disabled people, with phrases and terminology being used that can both cause offence and fail to recognise the humanity of

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[13] Furthermore, I did not want to just add Easy Read to my own work and consider this to be enough. Rather, I hope to play a part in normalising practices that enable outputs from research to be made available to learning disabled people. Accordingly, with support from a mentor, I instigated a business case within the University of Birmingham, to hopefully secure a PhotoSymbols licence and training package for all academics and students to use. This application for funding is still in progress, but I do hope that the importance of this business case will be seen, and that my efforts can contribute towards a force for change within how researchers consider approaching their research dissemination practices.

disabled people. Language choices made by researchers can perpetuate ableism, even if not intentionally (Bottema-Beutel et al., 2021). As disability rights advocate Ladau (2021:10) describes, there ‘isn’t one single way to talk about or think about disability’ but it is ‘important to *think about* how we *talk about* disability’. Bottema-Beutel et al., (2021:19) ask that researchers ‘reflect on the language they use in their written and spoken work, and use nonableist language alternatives’. Carey et al (2020:26) describe how language related to disability ‘is always controversial’ and there are ‘varied language conventions in play within different activist communities’. For example, NCDJ (2021) describe how ‘[e]ven the term “disability” is not universally accepted’.

Within this inquiry it is especially important to recognise the tensions between the language disabled people choose and the language that parents or professionals might use to describe disability. Corbett (1996:79-81) describes how professionals set the ‘vocabulary agenda’ and that disabled people ‘have been conditioned to listen to the voice of authority, to respect the language which defines their role and status’. They are expected to have deference towards professionals, especially the medical profession. Parents too are often required to describe their children using medical model to secure suitable support and education for their child. As Carey et al (2020:6) describe, some parents ‘align more closely with organizations led by disabled activists, while others organize in parent-led groups with distinct agendas’. Throughout this inquiry I have attempted to be a thoughtful, respectful, and informed ally to disabled people and to listen to their views regarding language, which has informed my approach.

3.6.1 Person first vs disability first

In the context of the broader conversation on illness, disability, and neurodiversity, both language and terminology are subjects of intense debate, as noted by Brown (2020). Ladau (2021:10) reminds us that the way ‘people who have a disability talk about their disability is *their* choice’ and everyone should respect these choices. She chooses to switch between saying ‘disabled person’ and ‘person with a disability’ to respect the two main ways that people refer to disability, namely ‘person-first’ and ‘identity-first’ language (Ladau, 2021:11). Person-first language ‘places the person before a diagnostic label in order to respect the holism of a person and the diverse identities a person may have’ (Carey et al., 2020:26). In this regard the individual is not ‘defined’ by their disability (Carey et al., 2020:26). Identity-first or ‘disability-first’ language ‘prioritizes the shared collective experience of disability and expresses the value of that experience’ (Carey et al., 2020:26). Advocates involved in the intellectual disability community will frequently use person-first language, whereas physically disabled or autistic activists tend to use identity-first language (Carey et al., 2020).

I recognise the complexities and tensions that exist surrounding the language that is used (Titchkosky, 2001; Shakespeare, 2006; Tobin, 2011), especially by non-disabled people such as myself. As someone who seeks to be an ally to the disabled people’s political movement, I intend to use identity first language throughout this thesis. If, however, I am referring to the work of a disabled person who uses people-first language, I will of course fully respect this in my use of their words. Therefore, I will be primarily referring to ‘disabled people’ throughout this thesis.

As mentioned in the introduction all the mothers who took part in this inquiry have children who have Down syndrome. Down syndrome is a genetic condition where people have the presence of all or part of a third copy of chromosome 21[14]. People who have Down syndrome can also be referred to as ‘intellectually disabled’, ‘cognitively disabled’ or ‘learning-disabled’. When I am discussing people who have Down syndrome, I will be using people-first language. As mentioned previously, people-first language tends to be the preference of self-advocates who have learning disabilities (Carey et al., 2020). Also, the UK leading Down syndrome charity *The Down’s Syndrome Association* describes how generally when discussing Down syndrome, person first terminology tends to be preferred, for example they state that you should use ‘a person who has Down syndrome’, or ‘a person with Down syndrome’ (The Down’s Syndrome Association, 2021).

3.6.2 Down’s Syndrome vs Down syndrome

The UK Down’s Syndrome Association describe how it is ‘is generally accepted that both Down’s syndrome and Down syndrome can be used interchangeably’ (Down’s Syndrome Association, 2021). They state that ‘[t]he use of the possessive apostrophe is a recognised model that is used for a number of conditions in Britain, thus, in the UK Down’s syndrome is used more commonly, whereas in other countries the more prominent is Down syndrome’ (Down’s Syndrome Association, 2021).

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[14] This is why Down syndrome is also sometimes known as Trisomy 21.

The term ‘Down’s Syndrome’ is an eponym, signifying that the term derives from John Langdon Down who originally described and classified the condition in the 1860s (Smith, 2010:3-4). Langdon Down believed there was a correlation between people’s abilities and their race and thought it possible to make a classification of the ‘feeble-minded, by arranging them around various ethnic standards’ (cited in Smith, 2010:4). He identified what he believed to be racial characteristics in some of his patients that stood out, which led him to identify a ‘Mongolian type of idiocy’, the language of which persisted into the 1960s (Smith, 2010:4-6). As Shakespeare (2012:1478) describes, Langdon Down was ‘[w]ildly wrong in his theory’. In 1959 Professor Jérôme Lejeune identified Down syndrome as a chromosomal condition, related to an extra copy of chromosome 21 (Smith, 2010). Langdon Down himself did not have Down syndrome, and his fascination with diagnosing and classifying can be seen to be ‘unhelpful to the inclusion of children and adults with intellectual disability’ (Shakespeare, 2012:1478). Given that there is no one preferred way of referring to Down vs Down’s Syndrome, for the purposes of this thesis I will use Down syndrome unless someone has specifically used the alternative, in which case I will remain true to their original words.

3.6.3 Special Educational Needs

‘Special educational needs’ or ‘additional needs’ are classifications applied to pupils who have been assessed by a professional as requiring different or additional education provision to meet their specific individual ‘needs’. The logic suggests that an individual’s unique educational needs can be discovered and assessed by professionals, and then additional provision can be planned and provided for to meet these needs. This leads to individual children being seen to have ‘a secondary, an additional claim to schooling and the pool of resources set aside for that social endeavour’ (Slee & Tait, 2022:2). As Veck (2014:181) describes, a ‘direct *correspondence*’ is established ‘between the identified “special” needs of students and the education they receive (original emphasis). Slee & Tait (2022:11) describe how the designation of Special Educational Needs was originally ‘borne from the unwillingness and inability of regular schools to educate all children’. This approach is underpinned by the ‘long-held assumption that individual “deficits” of children are the source of disablement in education’ (Slee & Tait, 2022:155). This leads to educational interventions designed to overcome their perceived difficulties, leaving external factors unaddressed and unaltered (Veck, 2014).

Over 25 years ago, Corbett (1996:2) claimed that ‘Special needs is becoming a most unacceptable term’. She contends that language of special educational needs ‘jars uncomfortably with the discourses in the disability movement’ because when ‘special’ is ‘applied to disabled people, it emphasizes their relative powerlessness rather than conferring them with honour and dignity’ (Corbett, 1996:33,49). And yet it continues to be widely used today. Despite this widespread use, I do not intend to use the language of ‘special educational needs’ in this thesis unless I am unable to avoid it, for instance when discussing policy or when quoting others who have used the term. Should I need to refer to special educational needs, I will use the terminology ‘categorised’ or ‘labelled as having special educational needs’ rather than saying that a child *has* special educational needs.

4. BEING ‘MUM’ IN THE ACADEMY

4.1 Introduction

My role and experience as a mother of a disabled daughter infiltrates every aspect of this inquiry. It would be impossible for it not to. I am resolute that motherhood and caring should not be hidden work within either the approach to undertaking research or within the production of this thesis. There are, without a doubt, challenges that are faced when studying or undertaking research whilst having significant mothering responsibilities, responsibilities that can be more intense and last for longer when your child is disabled. However, I also believe that, as Childers (2015:112) discusses, it is possible to think of the ‘mother-scholar’ as someone who can do ‘the work of disrupting the taken-for-granted and potentially opening up new thinking about motherhood and scholarship’. Although it can feel ‘like a radical act’ to talk openly about being a mother in academia (Bueskens & Toffoletti, 2018:14), rather than ‘subtracting motherhood’ and excluding the body, intimate relations, and the material conditions of mothering (Amsler & Motta, 2019:83-87), I contend that the addition of these has been vitally important to this doctoral research. Within this chapter I will therefore demonstrate how my role as a mother has influenced this doctoral research in positive ways, recognising ‘the validity of the ideas of women, mothers and those of different experiences who find themselves within the walls of traditional institutions such as the university’ (Summers & Clarke, 2015:237).


'Wanna preach about diversity? What have you actually done?'
DON'T FORGET
If you want to make that difference, you've got to get involved
Plant the idea
Every little change can make a big difference if each one of us makes them
"Why have we glued ourselves to the road again?" Says John.
possibly futile
IN REALITY, THINGS ARE DONE TO YOU, AND YOU OFTEN CAN'T DO MUCH IN RETURN
HELPS YOU UNDERSTAND WHAT YOU LIVE FOR
FEARLESS
Disruption
THE ANTIDOTE TO DESPAIR IS ACTION
CHALLENGE IT, CHANGE IT'
passionate about making a difference
united us with a common purpose
ANYONE CAN BE
Sculptors and sorceresses
you can make a difference
MY SOUL TRAIN where I was meant to be
Eat, sleep, heal, repeat
"I COULD NEVER HAVE DONE THIS ANY YOUNGER; IT JUST WASN'T IN ME"
LISTEN UP
VISIBLE WOMEN

4.2 Inquiry as activism

I have been on a journey towards greater involvement in parent activism since my daughter started in her education journey. Darling (1988:151) describes how negative experiences of the SEND system erodes trust in professional authority and can ‘serve as the turning point to launch parents’ activism’. Like many activist mothers, I did not ‘start out to change the world’ rather, I simply wanted to secure better opportunities and approaches to education for my own daughter; I might therefore be described as an ‘accidental activist’ (Pannitch, 2008:6). Runswick-Cole et al. (2022:307) describe how the lines between what counts as scholarship and activism are ‘inevitably blurred’. Within this inquiry, I have not sought to ‘maintain a respectable distance’ between my doctoral studies and my political activism as a parent (Runswick-Cole et al., 2022:308). Instead, I seek to make a real change in the world through my work, and like other mother-activist-scholars whose work I draw on heavily, I ‘have embraced scholarship as activism and activism as scholarship’ (Runswick-Cole et al., 2022:309-310).

Mothers of disabled children becoming activists in relation to education policy and practice is nothing new in the English education context. It is well documented that during the 1940s/50s mothers recognised the learning capabilities of their children who had been excluded entirely from education and began to challenge the ‘pervasive – and limiting – notion of ineducability’ as well as the dominance of medical professionals in their children’s lives (Webster, 2019:2). Women were meeting in their kitchens, protesting in their neighbourhoods and schools, forming organisations and lobbying governments (Pannitch, 2008:4). They began to lobby government for their children to have the right to education, and some came together and set up new special schools to improve outcomes for their children (Wedell, 2019). This subsequently led to the *Education (Handicapped Children) Act 1970*, granting all children of compulsory school age a legal right to an education, albeit not the right to an education in mainstream settings. Pannitch (2008:4) describes remarkable women, with ‘vision and tenacity’ who have created a legacy that can sometimes be taken for granted today. Although it is frustrating to think that 70 years later mothers are still having to engage in activism for their disabled children, I am proud to follow in the footsteps of these incredible women who chose to challenge the system, who spoke out, who stood together and who became experts in education and public policy.

It is important to recognise that there are tensions and a complicated relationship between disability activism and parent activists (Carey et al., 2020). Ryan & Runswick-Cole (2008:199) describe how mothers of disabled children ‘have occupied a complex, contradictory and marginal position within both disability studies and the disabled people’s movement’. I recognise that some disabled activists ‘perceive some parental activism as contributing to disability oppression rather than fighting against it’ (Carey et al., 2020:4). Aspis (2022) argues that parents should engage with the disabled people’s movement to support campaign work led by disabled people, rather than working within the establishment, eg. within universities, which results in disabled people being pushed out and unheard. She suggests that parent activists do not practice critical thinking and seek to maintain the status quo (Aspis, 2022). Within her discussion, Aspis (2022:155) also claims that parents ‘can never experience discrimination, exclusion, segregation, institutionalisation first hand like us as disabled people'. However, like Ryan & Runswick-Cole (2008), I believe that mothers of disabled children can also experience exclusion and disablism due to their close relationship with their disabled child. During my daughter's lifetime, I am the person who has noticed the looks and stares, who has spoken to a range of settings who have unashamedly excluded my daughter and has had to navigate a hostile and trauma-inducing education system to ensure my daughter had a meaningful education. Mothers of disabled children can also experience discriminatory practices and attitudes that disabled people face, some of which has become internalised (Knight, 2013). Therefore, to understand the exclusion and oppression of disabled children in education, the experiences, and understandings of mothers matter too, and these are the specific focus of this inquiry. Whilst I acknowledge that at times, as both a mother and researcher, I might be seen as part of the problem as Aspis suggests, I am keen to find ways to be part of the solution.

As Carey et al. (2020:257) explain, politicians 'gain by pitting parents against each other, parents against disabled activists, and different disability groups against each other', encouraging different groups to be 'scratching for scarce resources'. This can be resisted, and I believe it is possible for parents, scholars, activists and disabled people to come together to improve the lives of disabled people (Runswick-Cole & Ryan, 2019:1133). Such work must, however, be 'heavily influenced by the work of disabled scholars and activists' and therefore should reject deficit models of disability and the exclusion of disabled people (Runswick-Cole et al., 2022:311)[15]. Furthermore, it is necessary for mother-activist-scholars to be responsible for what we put out into the world (Runswick-Cole & Ryan, 2019). As I take this work

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[15] In the substantive theoretical chapters where I discuss affordances and belonging, I draw on the work of disabled scholars Garland-Thomson and Dokumaci.

forward, I hope to forge solidarities that ‘do not seek to eradicate or eliminate difference’, rather I recognise the importance of identifying synergies, articulating shared goals and collective visions, when we recognise our subjectivities as ‘anti-essentialist, relational and always incomplete’ (Routledge & Driscoll Derickson, 2015:392-3). It is possible for mothers and disabled people to act in solidarity with each other, as we negotiate our multiple and relational positionalities within a dynamic field (Routledge & Driscoll Derickson, 2015:392). It does not have to be an either/or situation but can be ‘AND... AND... AND...’ (Deleuze & Parnet, 1977:10).

4.3 Becoming a space invader

In this inquiry, I have embraced the complexity, otherness, and messiness that motherhood brings to the academy, to ‘bring in life’ in a way that pushes against and potentially transgresses some of the existing boundaries, to ‘embrace logics of being, creating, loving and thinking otherwise’ within an affirmative research practice (Amsler & Motta, 2019:90-3). Academia can sometimes be seen as a ‘male and childless space,’ where the ‘*ideal* academic worker’ is conceptualised as someone who is ‘married to the job’ and can meet increasingly high expectations for productivity within the neoliberalist university (Yoo, 2020:3174, original emphasis). Mothering responsibilities ‘are not governed by strict clock time,’ whereas university deadlines are (Lynch, 2022:14). Doctoral students who are also mothers/carers can frequently ‘face urgent and immediate care demands that have to be prioritised’ over static institutional deadlines (Lynch, 2022:14), which can be particularly challenging to navigate in practice. Mothers/carers therefore do not necessarily fit the mold of the ideal scholar and can be seen as bodies that are ‘out of place’ (Childers, 2015:117).

Motherhood can be silenced in universities (Low & Martin, 2019; Yoo, 2020). As Bueskens & Toffoletti (2018:15) claim, ‘too much of the mummy thing’ can risk one’s ‘credibility as a competent, capable and serious academic,’ meaning that mothers in academia might find themselves avoiding talking about their feelings and the issues that they are facing[16]. Mixing motherhood and academia can sometimes be seen as a ‘lethal cocktail’ (Munn-Giddings, 1998:56). However, I strongly believe that motherhood can also be reframed as a form of knowing, ‘as a valuable, plural subjective experience that brings much to alternative means of knowledge-production, to embodiment and care’ (Low & Martin, 2019:430). Mothering has the potential to provide new pathways and alternative ways of working that can challenge normative scripts of what it means to undertake research, by ‘unlocking different forms of understanding and knowledge-making and sharing’ (Low & Martin, 2019:430). As Amsler & Motta (2019:83-4) describe, although the role of ‘scholar-selves’ and ‘mother-selves’ are often seen as separate identities, it is possible to embrace these multiple subjectivities in a way that orientates towards ‘the creation of more integrated and unruly selves and knowledge practices’. As a ‘space invader’ (Amsler & Motta, 2019:85), being a mother in the academy can disrupt traditional approaches to knowledge production. As Childers (2015:112,124) suggests, mother-scholars can be a ‘disorienting multiplicity in constant becoming’ by offering ‘another ontology, another way of living and being in the

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[16] There are, of course, similarities here with how mothers of disabled children are expected to be objective and rational in their engagement, and not be ‘too mum’ or too emotional. As I discuss later in the thesis, some mothers in this inquiry discussed how they felt they needed to control their emotions in meetings.

academy and the world' that 'can be hopeful and productive'. She suggests that 'rather than inhabiting one subjectivity or another or supporting the binary' it is necessary to see the 'becoming mother-scholar' as an assemblage, 'engaged in multiple relations that unleash not only critique but new possibilities' (Childers, 2015:123).

Undertaking doctoral research requires deep continuous scholarship. Whilst it might be seen to be beneficial to find 'sustained quiet sitting in a peaceful place' which will allow one's mind to wander freely, with few external stimulants (Milroy, 2019:16-17), I have found limited opportunities to do this. Due to my additional responsibilities at home, I therefore needed to adopt more 'organic' temporal rhythms (Ulmer, 2017:203). I came to realise that 'like pregnancy' ideas cannot always be hurried (Summers & Clarke, 2015:245). Also 'alternative rhythms of inquiry' that 'run counter to the systemic beats of the academic metronome' (Ulmer, 2017:202) might be required to support their incubation. As Summers & Clarke (2015:245) describe, undertaking doctoral research and domestic or family duties can occur simultaneously, and there are benefits to this 'in-between' space where unformed ideas and creative practices can gestate. Therefore, I contend that the entanglement of my home life and my research has led me to be able to make connections or generate insights that might otherwise not have been possible.

Van der Tuin & Pekal (2023:48) discuss the benefits of 'serendipitous encounter,' where fascinating connections are made and unplanned for work commences that can push thinking further. They discuss the benefits of diffractively stumbling across a text or an image that reminds you of something else, where you find yourself 'conversing with a piece of scholarship, a philosophical idea, or a piece of art that needs unpacking and will lead to yet other texts or visual materials', which 'needs a lot of attention and a lot of care' (Van der Tuin & Pekal, 2023:48-49). They contend that for this to happen, it is necessary to have a solid disciplinary knowledge and background, and a 'desire to move away from reductive research and action' (Van der Tuin & Pekal, 2023:48-49). I have been open to such generative moments. It was therefore not only the conversations that took place with mothers in this inquiry that helped me think, but as St. Pierre (1997) describes, other aspects outside of the inquiry will inevitably have influenced the production of new knowledges. Emotions, senses, dreams (St. Pierre, 1997), embodied effects, chance conversations, passing thoughts whilst sat at the side of the swimming pool during my daughter's swimming lesson, 'AND... AND... AND...' (Deleuze & Parnet, 1977:10) have all had an impact on this inquiry, leading to new directions and possibilities. At times it became difficult to know where the doctoral research started or finished. The intra-action (Barad, 2007) of my home life and my doctoral research has led to 'a complex web of objects, bodies, intensities that connect momentarily to generate something new' (Higgins et al., 2017:22). Mothering has provided greater complexity within this study, generated new insights about both how to undertake research and has informed the emerging threads and knowledges produced within this thesis.

4.4 Drawing on my experience as a research participant

Since my daughter was born, 19 years ago, both she and I have been participants in a range of research studies. My daughter has been observed, had her DNA analysed, her brain waves monitored, been asked to undertake a range of activities and, more recently has been asked to articulate her experiences of support and services. I have not only accompanied and supported my daughter to meet researchers, but have also completed numerous surveys and questionnaires, been interviewed, attended focus groups and told our ‘story’ repeatedly.

It is unusual for researchers to be participants in research themselves, despite this being seen as beneficial for designing an inquiry, and there is ‘scant literature on the experience, value, and challenge of inhabiting dual roles when researchers are members of the group they are investigating, or actual participants in a study’ (Probst, 2016:unpaginated). Being both participant and researcher can ‘foster an appreciation for mutuality, reflexivity, co-construction, and respect for both the knowledge and vulnerability of interviewees that cannot be learned simply by reading about it’ (Probst, 2016:unpaginated). I believe that my extensive experiences of being a research participant was generative within this research process. Although Dennis (2014:397) argues that it is worth taking participants’ experiences into account because we ‘want to be able to anticipate how participants will respond to and react to our engagements with them,’ this is not my intention here. Indeed, I do not believe it is possible to predict how a participant will react within research engagements that are a ‘co-constructed encounter’ within which subjectivity is ‘“created, recreated, disrupted and repaired within social interaction”… rather than an exchange between two discrete entities’ (Probst, 2016:unpaginated). However, I wanted to use my experiences as a participant to imagine how research could be undertaken differently, with an over-arching aim of making the research experience more positive for the mothers who were willing to give up significant amounts of their time.

My experiences as a participant	**My response within this inquiry**
Not knowing anything about the researcher or their motivations. Sometimes only knowing their name and institution and the basic information about the nature of the study.	• Including information about myself and why I want to undertake this research within the information provided to all parents interested in taking part in the inquiry. • An introductory telephone conversation before parents signed the research agreement/consent form, in which I introduced myself and my interests in undertaking this research. This also provided an opportunity to explain how this research, as a conversation, differs from a standard interview. • By using 'conversation' as the research method I bring myself into the inquiry, thereby opening myself to have my understandings and approaches questioned and discussed openly within the research engagement. For instance, we would discuss my daughter's journey through education and what went well or not. • A shared 'agreement' forming the basis of the consent form, setting out my

	commitment to parents as part of this inquiry[17].
Not knowing the research outputs or how our ‘data’ was being utilised. Not always being provided with a copy of the final research. Researchers using only a small part of the content, eg from an interview, to argue a particular position in their article, when most of the discussion would have suggested an alternative position or story. Feeling as though the real story I wanted to tell was being silenced (Dennis, 2014:404).	• Exploring ideas together in conversation, so that the analysis takes place within co-created in the research encounter rather than data being extracted and used. • Ensuring that parents are happy with how they are represented in any research outputs, for instance when using their words. • Providing parents with the opportunity to read the thesis in draft form, so that they can comment on it before it is submitted. I will incorporate their comments into the final draft. • Keeping parents updated on research outputs, again seeking their input and ideas. • Providing parents with a copy of the final thesis on completion for their thoughts and feedback.
Researchers choosing a pseudonym for my daughter that I did not like.	• Allowing parents to choose their own pseudonyms[18].
Leaving an interview or focus group situation feeling that I have not explained myself clearly or wanting	• An ongoing conversation where we can return to previous discussions, providing an opportunity for parents to change their

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[17] See Appendix Five

[18] See further discussion on pseudonyms in Chapter Seven

to add more depth/clarity to what I had said. Wishing I had not said something but feeling it was too late to change what I had said.	minds, to provide further explanation or to correct any potential misunderstandings. • Transcripts provided for participants not just for checking for accuracy but also to allow them to review and reflect on our conversation, and to be able to discuss any elements that they wanted removing or that they had reflected on and wanted to discuss further in the next meeting.
Circumstances changing quickly. Agreeing a time to meet but then finding this clashed with other pressures as a parent of a disabled child.	• An ongoing conversation where updates to any individual situation could be discussed and incorporated into the research inquiry. • Allowing parents to choose how, when and where we meet (being as flexible as possible, subject to my own availability), to ensure that the inquiry fits in with their life and schedules. • Checking in with parents on the day of each meeting or call to check that they were still in a position to meet and reminding them that it would be fine to postpone if they needed to.
Feeling limited to the time allocated by the researcher for the interview or focus group when I had more detail that I felt was important to include.	• Allowing enough time for each conversation to flow, ensuring that I did not book meetings or calls when I had something immediately afterwards. • Asking parents before we meet how long they had for each meeting and giving them

	the opportunity to book another meeting or add further detail by email.

4.5 Positionality

As Childers (2015:124) describes, 'mother-scholar is an assemblage that arises from the in-between.' There is 'no inside or outside', no clear divisions between myself, my mothering, and the inquiry, instead there was a continual process of 'folding, unfolding, refolding' (St. Pierre, 1997:178). My subjectivity is continually being produced in relation, where I was produced as mother-scholar through 'multiple relations that unleash not only critique but new possibilities' (Childers, 2015:123). This therefore offers a challenge to the requirement to produce a traditional positionality statement. My positionality cannot be neatly mapped as insider or outsider, rather it is necessary to recognise subjectivity as being located 'within shifting networks of relationships' where there are many factors that could contribute to biases, assumptions and how those engaged in research might relate to each other (St. Louis & Barton, 2002:pt2).

Insiders are those whose biography or identity markers give them membership or familiarity with the people who are being researched due to sharing attributes, or privileged access to that group, whereas the outsider has no intimate knowledge prior to the research relationship and is seen to not belong in at group (Mercer, 2007). As Hayfield & Huxley

(2015:92) describe, it is suggested that ‘insiders are more aware of the lives of their participants than outsiders and are therefore in a strong position to conduct ethical research which keeps (often marginalized) participants at the top of the research agenda and represents their voices’. Within this inquiry, I might be seen as having insider researcher status, because I am a parent of a disabled child in the same way that the parents who took part in the inquiry are too. I engage in the same SEND policy landscape and may experience similar issues to the parents engaging in the research, allowing me to have empathy and understanding. Accordingly, I might be seen to have an advantage over outsiders ‘in terms of developing nuanced and meaningful’ research because of my familiarity with the types of issues that affect other parents’ lives meaning that I could be seen as someone who can intrinsically understand (Hayfield & Huxley, 2015:95-97).

Yet, as Shah (2006:211-2) describes, ‘only part of my life history resembled that of each respondent’, so it is necessary to not assume ‘too much commonality of perspective’. Furthermore, sharing aspects of positionality do not necessarily automatically lead to a particular predisposed point of view, and it is ‘important not to make any assumptions about others’ perspectives as this can lead to pigeon-holing based on our own understandings and conceptions of the other (Holmes, 2020:2). The insider/outsider binary can paint a simplistic either/or picture, whereas ‘insiderness’ and ‘outsiderness’ are constantly shifting throughout the research, and possibly even within the same interaction (Bukamal, 2022:244-5). I do not see myself as ‘switching channels’ (Yoo, 2020:3180) or having a ‘divided’ self (Amsler & Motta, 2019:84), rather my multiple roles and experiences cannot be neatly separated out as they intra-act (Barad, 2007) and become together in assemblage.

Of course, it is impossible to avoid the fact that I am being inducted into the academic community as I undertake doctoral research. Immediately this sets me apart from the mothers who are participants. I understand the ’position of privilege’ that exists by being part of the academy (Runswick-Cole et al., 2022:321). Further, I recognise that as a researcher it is possible that my ‘voice’ might carry greater epistemic weight than the voices of other parents by very nature of being positioned as a scholar and not ‘just’ a parent. Runswick-Cole et al. (2022:321) suggest that mother-scholar-activists need to be aware of this privilege and the corresponding potential for oppression, meaning that we must also work to ‘share knowledge and resources within and beyond our networks wherever possible’[19]. By doing so, it becomes possible to create new spaces where mothers of disabled children can talk about disability and the impact it has on family life. I feel an additional sense of responsibility as a mother of a disabled child who is undertaking this research to ensure it makes a difference and it is my intention to do this within and beyond this research inquiry.

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[19] I discuss how I have done this in Chapter Twelve

5. FACTORS THAT SHAPE AND INFORM THE INQUIRY

5.1 Context

In this section, I discuss the educational landscape and policy context with a particular focus on the roles that parents have either been ascribed or have shaped for themselves. Through this discussion I will demonstrate why this research inquiry is timely and relevant for current policy development in relation to the changing role of both parents of disabled children and current shifts in policy narrative which are purported to lead to more children being educated in mainstream education.

5.1.1 Inclusive education

As previously mentioned, there are diverse views amongst academics/researchers about inclusive education (Allan & Slee, 2008). There are also diverse views amongst parents and teachers (Nilholm, 2020). Byrne (2022:301) suggests that the 'seemingly innocuous phrase "inclusive education" belies its internal controversy'. Whilst there 'seems to be a general consensus on the value of inclusion,' however 'inclusion' is being defined, 'there is little agreement on what this actually means in an educational context' (Terzi, 2010:2-3). There are 'many contrasting and opposing views as to what counts as a special educational need and/or a disability' as well as 'where these pupils should, or should not, be educated' (Hodkinson, 2020:312)[20].

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[20] Although this inquiry focused on the English context, it is also important to recognise that inclusion will also be conceived in different ways within different cultures and educational systems (Nilholm, 2020).

It is often suggested that the field of inclusive education is divided in two – with the ‘inclusionists’ on one side, arguing for ‘full inclusion’ where all children are educated together in mainstream schools, and the ‘special educationists’ who argue that inclusion is ideological and placing disabled children into mainstream education causes them harm (Allan, 2008:12). Those in the field advocating for ‘full inclusion’ argue that specialist education settings are exclusionary and suggest that the possibility of developing a fully inclusive education system is ‘compromised by the very existence of special schools and special classes’ (Tiernan, 2022:884). Whereas those who oppose this view hold a position ‘that special education is needed to ensure the appropriate education of all children, including the exceptional’ and that ‘imagining appropriate education for all without special education is untenable’ (Kauffman et al., 2022:2). Norwich (2022:4) describes how both advocates of ‘full inclusion’ and their critics mirror each other’s kind of thinking, using dichotomies and oppositions; he suggests however that more nuanced approaches can identify strengths and weaknesses in these binary arguments. I briefly discuss the main positions below.

Kauffman et al. (2022:2-3) describe how over recent decades there have been many attempts to ‘improve, change, or modify special education’, with efforts being largely influenced by what they call the ‘full-inclusion movement’. They suggest, however, that the ‘full inclusion’ of all disabled students in mainstream education requires completely reimagining the state school system. They suggest it is more realistic to imagine mainstream education in a way that does provide ‘improved accommodation’ of disabled children which can improve the education of many, however they contend it is ‘dangerously naïve’ to think that mainstream schools can teach all disabled students appropriately (Kauffman et al., 2022:6). Kauffman et al. (2023:206) suggest that disability ‘is a unique kind of diversity that requires responses different from those of all other diversities’ further arguing that schools should be ‘fully inclusive of diversities other than disabilities’ because they can be ‘relatively easily accommodated’ without ‘drastic changes in instruction’. Hornby & Kauffman (2024:5) suggest a more ‘pragmatic path’ is needed, which includes specialist education for pupils who are learning-disabled as this is the most appropriate setting for them.

Yet those who argue for a conception of inclusive education that does not include specialist provision, for instance Allan & Slee (2019:4), are ‘unwilling to give up’ on inclusive education and disagree that inclusion ‘doesn’t work, and it has never worked’. Instead, they argue there has never been ‘sufficient means, motive and opportunity’ for full inclusion to materialise (Allan & Slee, 2019:5). Rather, disability and inclusion policy has always been ‘an (inferior) relation to the mainstream’ where inclusive education has been ‘relegated to a technical matter’ and the enduring system of ‘special education continues to be kept alive’ due to its use ‘as a receptacle’ for those that mainstream educators are ‘unable or unwilling to teach’ (Allan & Slee, 2019:3-6).

In the English education landscape, education provision for disabled students relies on ‘a system built on the categorisation of “special educational needs”’ that was introduced following the Warnock Report (DES, 1978; Hodkinson, 2020:311). Schools were developed with ‘typical’ able-bodied able-minded pupils in mind, and were never meant for everyone (Allan, 2008; Allan, 2010; Goodley, 2021). Disabled pupils were an afterthought. Indeed, it was not until 1981 in the UK that all children had a right to an education, because of parents lobbying for their children to be included. Yet, the idea that all pupils should be educated together in one setting still has not been universally accepted by professionals or parents (Allan & Slee, 2008). Originally the ‘special educational needs’ of disabled pupils resulted in them being taught in separate schools or classrooms. Their inclusion in education was considered a benevolent act, caring for ‘weaker’ members of society (Tomlinson, 2014:15). Special education became established as ‘an important structural component of the educational system’ for children who that were deemed incapable or unwilling to participate in the ‘“normal” curriculum’ in state education (Tomlinson, 1985:158). The field of special education was primarily concerned with assessment, diagnosis, and treatment. Research focused on generating effective educational approaches that could be implemented as interventions to meet individual needs. The focus of special education therefore was ‘marked by a need to know how many, what sort of problem and what to do about it’ (Tomlinson, 2014:21).

During the 1970s and 1980s the separation of disabled pupils who needed ‘special services’ started to be questioned and discussions about inclusion came to the fore (Tomlinson, 2014). The ‘conventional narrative of special education as a reasonable, ethical, effective response to the fact that certain children have disabilities or special needs’ started to be critiqued and there was concern about the ‘social production of childhood pathologies as well as development of professions and organizational systems to control and treat those disorders’ (Danforth & Jones, 2015:8). Education scholars felt that educational policies and research literatures supporting special education provision were ‘deeply flawed’ and it was from this challenge to the theory and practice of special education that the field of inclusive education emerged (Danforth & Jones, 2015:3). The first step towards education reform was ‘integration’, where disabled students who did not disturb others could be placed in ordinary classrooms with special supports (Danforth & Jones, 2015:13). There was no political desire to substantively transform schools, instead the onus was placed on the pupil to ‘fit in’ (Danforth & Jones, 2015). Danforth & Jones (2015:14) argue that integration had simply ‘preserved the ideologies, theories, and practices of special education, proceeding as if the entire professional culture built to sustain segregation must be maintained’ and there had been a lack of authentic change. I suggest that we have still not moved beyond this stage.

Hodkinson (2020:311-2) argues that there has only ever been a ‘rhetorical guise’ of inclusion, as educational practice still frames disability as deficit. From 2010, with the Coalition Government[21] in power, there was a ‘fundamental shift in ideology’ (Hodkinson, 2020:320) with a stated intention to ‘end the bias towards inclusive education’ (Runswick-Cole, 2011:112). Runswick-Cole (2011:112) describes how this implies there had previously been a ‘bias towards inclusion’. Instead, she argues, ‘although there may have been an inclusive education policy rhetoric, this rhetoric is rooted in conceptual incongruities which, rather than promoting inclusion, undermine an inclusive approach to education’ (Runswick-Cole, 2011:112). It is important to note that whilst the Labour government in the late 1990s claimed to be committed to inclusive education, their education policies led to more children attending special schools than ever before.

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[21] The Conservative and Liberal Democrat parties formed a coalition government in May 2010.

In March 2011, the Government published a Green Paper '*Support and Aspiration: A new approach to special educational needs and disability*' which reinstated the commitment to 'remove the bias towards inclusion' stating that there was an intention to 'prevent the unnecessary closure of special schools' (DfE, 2011:5). Subsequently *The Children & Families Act 2014* received Royal Assent in March 2014 and came into force on 1 September 2014. The reforms were seen as ambitious, designed to transform the educational experiences of pupils labelled with SEND. The main structural change within the reforms was the introduction of Education, Health and Care plans (EHCPs) for children and young people from 0-25 years replacing Statements of Special Educational Needs. Pupils labelled as having SEND whose needs can be met in a mainstream setting without additional provision set out in an EHCP would have their needs met by an 'Assess-plan-do-review' graduated response within a new category of 'SEN Support'[22], replacing the previous School Action and School Action Plus categories.

It is significant to note, however, that the term 'inclusive education' does not appear within the SEND Code of Practice that accompanied this new legislation (DfE & DHSC, 2015). As Allan & Youdell (2017:75) describe, 'where the notion of "inclusion" appears it is a vague and mobile notion that seems to also contain the possibilities of separation'. The SEND system continues to be based on individual deficit, framed as special educational needs, and there continues to be a 'highly segregated education system, simply coated under the rhetorical disguise of inclusive practice' (Hodkinson & Burch, 2019:157). Hodkinson & Burch (2019:157)

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[22] SEN support means support that is additional to, or different from, the support generally made for other children of the same age in a school. It is provided for pupils who are identified as having a learning difficulty or a disability that requires extra or different help to that normally provided as part of the school's usual curriculum offer.

suggest that ‘it is perhaps comforting to buy into the belief that our education system has moved far beyond the exclusion of children based upon the categories of “educationally sub-normal” and “maladjusted”’, yet maybe ‘the progression of educational provision is not as advanced as we like to think’.

In 2017, the UN Disability Committee undertook scrutiny of the UK Government’s implementation of The UN Convention on the Rights of Persons with Disabilities. They noted the ‘persistence of a dual education system that segregates children with disabilities in special schools, including based on parental choice’, the increasing number of pupils in specialist provision, insufficient training for teachers in inclusive competencies and an education system that ‘is not equipped to respond to the requirements for high-quality inclusive education’ (Committee on the Rights of Persons with Disabilities, 2017). In 2020, the Global Education Monitoring (GEM) report still ‘painted a picture of inclusion as very much a work in progress’ (Webster, 2022:6). Webster (2022:7) suggests that the slow progress is not a surprise given the ‘the numerous and nuanced cultural and political battles for hearts and minds that must be won within each individual education system, and… the considerable effort to remake physical spaces, develop the education workforce, and devise practical innovations regarding pedagogy, curricula and assessment’. He further suggests that whilst there continues to be a rhetoric of inclusion, it remains ‘an illusion’ in English schools, where the reality is that pupils categorised as having SEND are not fully included, with the preservation of mainstream education for ‘typically developing students’ and a ‘diluted pedagogical offer for pupils with high-level SEND’ (Webster, 2022:2).

Ultimately, despite there being a promise of transformative change and reduced conflict within the SEND system, the ambition of the reforms failed to be realised. In 2019, The House of Commons Education Select Committee, as part of their post-legislative scrutiny, found that families continue to bear much of the responsibility within the system, having ‘to wade through a treacle of bureaucracy, full of conflict, missed appointments and despair’ and that children and young people continue to be let down by a lack of joined up working and opportunities (House of Commons Education Committee, 2019:3-4). They found that there was a clear ‘absence of responsibility for driving change’ and the system remains ‘adversarial’ and ‘hard to navigate’ (Long & Danechi, 2022:39). The Committee also ‘found significant concerns about the financial sustainability of the system and systemic problems in its operation’ (Long & Danechi, 2022:6), and concluded their report by stating that ‘[f]amilies are in crisis, local authorities are under pressure, schools are struggling’ (House of Commons Education Committee, 2019:83).

Ofsted SEND local area inspections similarly found that children labelled as having SEND had ‘a much poorer experience of the education system than their peers’, access to therapies remains difficult, children and parents are not sufficiently involved in planning and reviewing provision, and that a ‘large proportion of parents in the local areas inspected lacked confidence in the ability of mainstream schools to meet their child’s needs’ (Long & Danechi, 2022:50). From 141 local areas SEND inspections that took place before March 2022, 76 resulted in a ‘written statement of action’, signifying ‘significant weaknesses’ in their SEND provision (GOV.UK, 2022:8).

5.1.2 A growing ‘problem’

In January 2023, there were approximately 1.6 million school pupils in England identified as having SEN, of which around 1.2 million receive SEN Support in mainstream education (Long & Roberts, 2024:34). Approximately 390,000 pupils in school had an EHCP in 2023, compared to approximately 233,000 school pupils holding Statements[23] in 2007 (Long & Roberts, 2024:34). The proportion of pupils holding an EHCP continues to rise, reaching 4.3% in 2023 (Long & Roberts, 2024:35). In January 2023, 33% of pupils holding an EHCP were attending special schools (Long & Roberts, 2024:37). It has been argued that the increase in EHCPs is due to a lack of confidence in the SEN Support offer in mainstream schools and the need for schools to secure additional funding that might be attached to an EHCP (Lamb, 2021). This rise in EHCPs has been described as ‘unsustainable’ (Lamb, 2021:37).

As the Education Select Committee (2019:3) described, the 2014 SEND reforms ‘resulted in confusion and at times unlawful practice, bureaucratic nightmares, buckpassing and a lack of accountability, strained resources and adversarial experiences, and ultimately dashed the hopes of many.’ Several reasons have been presented for this failure, including the impact of austerity measures, challenges in joint commissioning in practice with different legislative frameworks in place, changes to curriculum and accountability within mainstream settings, inadequate implementation and lack of accountability measures (Lenehan, 2019; House of Commons Education Committee, 2019). Lamb (2018:166) suggests that ‘recourse to the legal

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[23] Statements of Special Educational Needs, which were introduced following the 1978 Warnock Report, were gradually replaced with EHCPs following the Children & Families Act 2014 coming into force.

system over individual decisions around EHCPs can be seen, in part, as a barometer of how well the new system is working'. It is telling, therefore, that the number of complaints and tribunal hearings have significantly increased since the reforms were introduced, as shown in the infographic below:

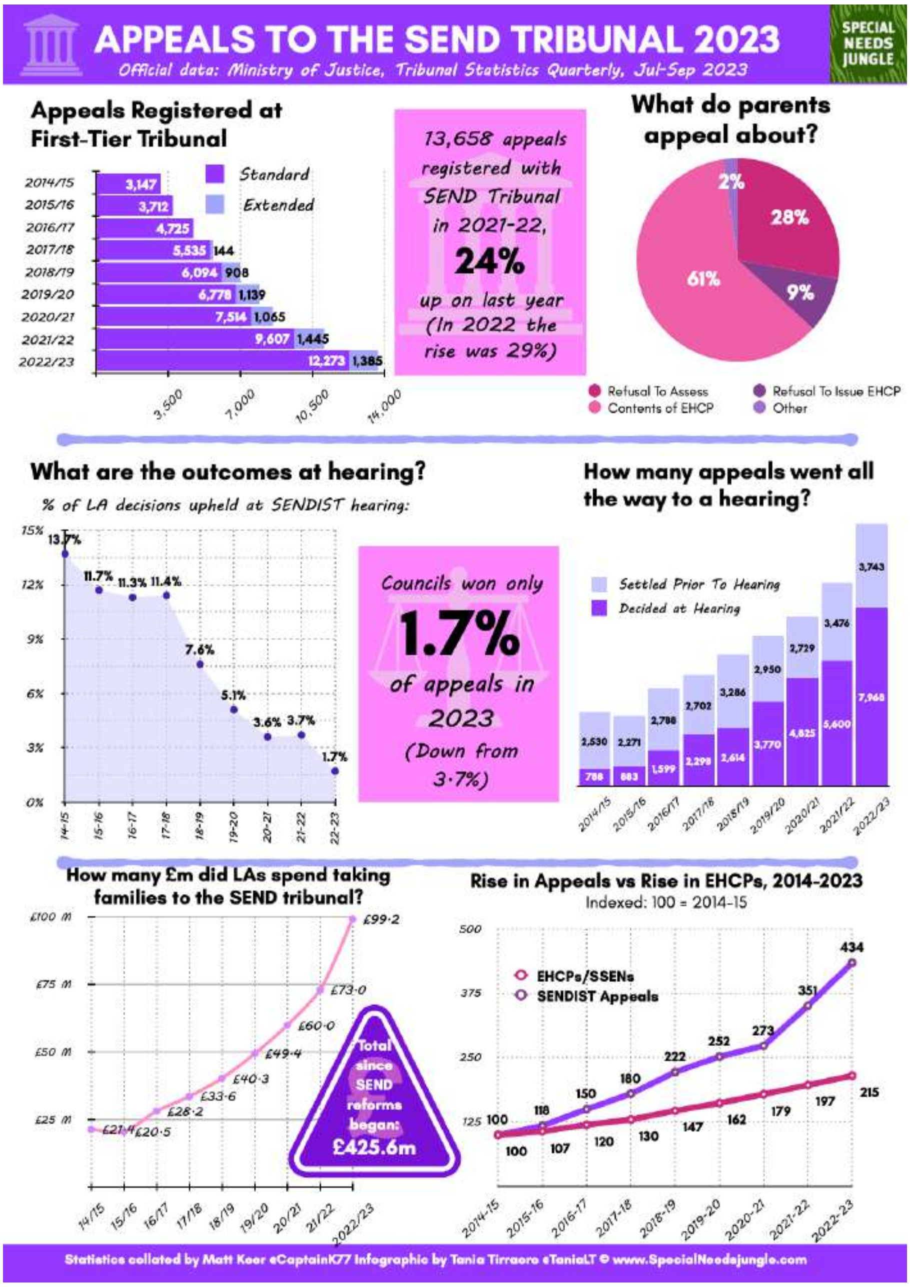

Image 5: SENDIST Appeals
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5.1.3 The wider education context

The English education system is currently based on a neoliberal ‘investment model’ where pupils, teaching staff, school leaders and parents are required to make decisions based on future returns for their child and wider society (Ball, 2021:214). Since the late 1970s, with reforms introduced by the Thatcher Government[24], education in England has been based on a ‘standards agenda, based on neoliberal notions of accountability, assessment and performativity’, which led to the introduction of a National Curriculum[25], SATS[26], school league tables, Ofsted inspections[27] and a ‘competitive ethos in schools’ (Williams-Brown et al., 2022:1). In 2013, the DfE announced a revamp of the national curriculum and reform of GSCE examinations, moving away from modular assessment in a return to terminal exam-only assessments, with greater focus on spelling, punctuation, and grammar (Ball, 2021). There has also been a widespread narrowing of the curriculum, which can mean there are fewer suitable options for pupils, including those who are labelled as having SEND, who might benefit from vocational options or on ongoing modular assessments that do not require the retention of large volumes of information. The standards-led educational environment offers challenge to the effective inclusion of disabled children. Williams-Brown et al. (2022:3-10) suggest that inclusion has not been successful in practice due to being subsumed within and perverted by the ‘hostile environment’ of the standards agenda which

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[24] 1979 to 1990

[25] Introduced in 1989, the National Curriculum is a set of subjects and standards used by primary and secondary schools to ensure that all children learn the same things. It covers what subjects are taught and the standards children should reach in each subject.

[26] Introduced in 1988, Statutory Assessment Tests: These tests, alongside teacher assessment of English writing and science, are used to measure school performance.

[27] Founded in 1992, Ofsted is the Office for Standards in Education, Children’s Services and Skills. They inspect services providing education and skills for learners of all ages and also inspect and regulate services that care for children and young people.

prevents curricula and other aspects of education from being adapted to include those who have additional needs.

There have also been further changes to school governance, accountability, and funding models since the Coalition Government came into power in 2010. As Ball (2021:214) describes, the state now funds and manages the education system ‘using performance measures and requirements to “steer at a distance”’. Schools are both ‘encouraged and required’ to become ‘more like businesses’ within an ‘education marketplace’ (Ball, 2021:21). There is an ongoing requirement to raise performance levels, with even greater emphasis on accountability measures and school league tables. Schools, in a desire to be seen as effective, can be seen to prioritise ‘proxy goals of passing tests, hitting targets and climbing league tables’ and the necessary ‘tactics for passing, hitting and climbing them’ (Astle, 2017:2,5). Pupils who are categorised as having SEND can therefore present a challenge, or a risk, to schools being seen as effective, as they may disrupt the education of others and/or have a negative impact on school results. Accordingly, they may be turned away or excluded from schools to protect school results.

Further, in 2010, Michael Gove (then Secretary of State for Education) ‘unleashed the most significant change to the structure of the education system in decades by allowing all schools to convert to academy status’ (Freedman, 2022:4)[28]. These changes furthered reforms

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[28] Academy schools are state-funded schools that are independent of local authorities, instead operating according to a funding agreement with the Secretary of State. Academies are run by trusts, which are charities and not for profit. Academies do not have to follow the national curriculum, they do not have to employ teachers with qualified teacher status unless required by their funding arrangement, and local authorities have very little involvement in how they operate, unlike maintained schools (Roberts & Danechi, 2019).

introduced by Kenneth Baker (then Secretary of State for Education) in 1988 which allowed schools to 'opt-out' of their local authority (LA) and extended the Academies programme developed by Tony Blair's Labour Government[29], which was perceived to be successful in raising standards (Freedman, 2022). The academisation agenda leads to a weakening of LA control of schools, with a shift towards a market-led 'self-improving system' (Freedman, 2022:9). By January 2023, 40.4% of primary schools and 80.4% secondary schools were either Academies or Free Schools. Multi-Academy Trusts (MATs)[30] are seen to be the 'bedrock' of 'an ever improving and fairer system' where effective schools provide support to those needing improvement (Freedman, 2022:33). This therefore presents a complex education system, where some schools are maintained by local authorities and others are run as either standalone free schools/academies or are part of MATs of varying sizes. This dual system can be confusing for parents to navigate and offers complex arrangements for school accountability (Freedman, 2022). Academies are responsible for their own admissions arrangements, and it has been suggested that some are reluctant to accept pupils who are categorised as having SEND (Reeve, 2016).

Although schools are encouraged to embrace differences within a supportive culture, there is also a need for them to identify the 'Special Educational Needs' of some learners, framed in deficit language, to provide individual support to these pupils (Naraian, 2020). Within the dominant accountability culture, schools must manage difference in a way that the education and progress of most pupils remains unaffected (Allan, 2008; Allan & Slee, 2008). Schools

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[29] 1997-2007

[30] A Multi-Academy Trust (MAT) or an academy chain is an Academy trust that operates more than one Academy school. A small number of MATs include 40 or more schools, but most have between 1 and 10 schools (Roberts & Danechi, 2019).

need to effectively 'monitor, calibrate and segment' their pupil population (Slee, 2019:914), through which some pupils become positioned 'as failures' (Allan, 2008:10), as pupils whose needs cannot be met, as pupils who do not belong. The 'problem' therefore becomes located within the child and can lead to the idea that some students cannot be included within a mainstream classroom because their needs are too complex and teachers have not had sufficient training. This can lead to justifications for the exclusion of some children from mainstream education or schools being reluctant to enrol disabled pupils (Slee, 2019). Students who cannot meet the performative demands of mainstream education are subsequently encouraged to attend specialist educational provision. Parents quickly become very aware that some mainstream schools 'don't want their children' (Seabrook, 2023).

Finally, the current Government sees education as playing an important role in their 'broken society agenda' with a focus on 'poor pupil behaviour' and 'troubled families' (Ball, 2021:20). They have called for greater discipline and authority in schools, which has led to controversial 'zero tolerance' behaviour policies being implemented in some schools and MATs (Busby, 2018; Dickens, 2020). There are an increasing number of advocates for traditional teaching methods alongside strong discipline, which can be seen to lead to improved attainment for pupils in disadvantaged areas (Birbalsingh, 2022). These methods and behaviour policies can lead to some pupils who are labelled as having SEND from being punished or excluded because of their additional needs (Marvin, 2018). Though of course, some pupils might find comfort in clear expectations and quieter classrooms.

5.1.4 Further SEND reform during this research inquiry

This doctoral study started one month after the UK Government announced a major review into support for children labelled with SEND (DfE, 2019). The SEND Review aimed 'to improve the services available to families who need support, equip staff in schools and colleges to respond effectively to their needs as well as ending the "postcode lottery" they often face', in particular to understand how it 'can be made to work best for all families' and can 'boost outcomes and improve value for money' (DfE, 2019:unpaginated). However, the Covid pandemic delayed the process. It was therefore not until March 2022 that the *SEND Review: Right support Right place Right time* Green Paper was published, setting out proposals that the Government claimed would 'ensure that every child and young person has their needs identified quickly and met more consistently, with support determined by their needs, not by where they live' (GOV.UK, 2022).

Before publishing the SEND Review proposals, the Government also introduced two new programmes, designed to bring SEND budgets back under control: Safety Valve Intervention[31] and the Delivering Better Value in SEND[32] (DBV) Programmes. As Carter (2023:107) explains, these programmes provide 'funding to resource system-wide changes' to address the unsustainable pressure of increasing numbers of EHCPs and associated school transport costs. A primary aim of these interventions is that LAs need to manage demand for EHCPs

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[31] The Safety Valve programme is targeted at Local Authorities with the highest Dedicated Schools Grant (DSG) deficits. Additional funding is provided on the condition that the Local Authority cuts their deficits, for instance by moving more pupils into mainstream education. At the start of the programme there were 20 LAs, but others have joined since. There are now 34 LAs in the programme.

[32] The DBV programme was introduced as an optional programme, which was taken up by 55 Local Authorities that had less severe deficits than those in the Safety Valve programme. LAs eligible to join were chosen due to having high deficits.

through the more effective use of mainstream education placements (Carter, 2023). And yet, as Carter (2023:109) explains, ‘LAs have no direct control or authority’ over most mainstream schools that are now Academies or Free Schools, and part of the problem is that local government no longer manages these settings.

The Green Paper proposals that followed in 2022 focussed on increasing consistency and setting out clear national standards that pupils labelled with SEND should expect to receive within an aspirational and ambitious single national system (GOV.UK, 2022:5-6). Three key challenges are identified, one of which is a concern that ‘the system is not equally accessible’ as ‘parents and carers with access to financial and social resources are often better placed to navigate the system and secure support for their child’ (GOV.UK, 2022:10). The Government describe a ‘vicious cycle’ in which the increased number of pupils being placed in out of area specialist provision or independent specialist provision ‘even when this may not be best for them’, meaning that both financial resources and workforce capacity are ‘pulled to the specialist end of the system’, reducing resources available for those in mainstream settings (GOV.UK, 2022:13). The insinuation here is that well-resourced parents are taking more than their fair share, causing issues for other families. This is also the position taken by the Local Government Association who commissioned research about disagreements and disputes in the SEND system in England in 2022 (Bryant et al., 2022). One of the key challenges Bryant et al. (2022) identified was how more families are seeking formal redress, eg. via the SENDIST Tribunal, employing advocates and solicitors to do so. They suggest that this creates inequity in the system, where only the most able and financially resourced families can secure the ‘golden ticket’ of an EHCP (Bryant et al., 2022; Smith, 2023)[33]. LA leaders situate the problem with ‘articulate, middle class parents’ who are demanding provision that their children might not need but are able to challenge LA decision making (Bryant et al., 2022:35). They describe a situation where there is ‘increasing demand for statutory provision depleting capacity for preventative services’ (Bryant et al., 2022:53). They therefore suggested it will be necessary to ‘rebalance the SEND statutory framework’ to reduce demand on specialist services and to increase the number of children whose needs are met within mainstream educational settings (Bryant et al., 2022:51). The problem with the SEND system is being positioned as a demand-led problem, with parents wanting more than their children need.

Interestingly, the 2022 Green Paper proposals attempt to ‘respond to the need to restore families’ trust and confidence in an inclusive education system with excellent mainstream provision that puts children and young people first; and the need to create a system that is financially sustainable and built for long-term success’ (GOV.UK, 2022:5). However, whilst an increased focus on inclusion and improving mainstream education would be welcome, there is little within the Green Paper setting out how this would be achieved. The *SEND and alternative provision improvement plan* was published in March 2023 (DfE & DHSC, 2023) setting out an intention to create a system that is financially sustainable, which requires greater parental trust in mainstream education to reduce demand for expensive specialist placements.

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[33] I discuss this further in Chapter Ten

Various elements of the new national SEND and alternative provision system now need to be tested. The proposals set out a vision of creating ‘a more inclusive society’ which will require ‘improved, high-quality mainstream provision where children and young people have their needs identified early and can access prompt, evidence-based, targeted support’ (DfE & DHSC, 2023:22). However, the proposals lack detail about how mainstream schools will become more inclusive, nor do they set out what ‘good inclusion’ is. It seems that they are seeking an increase in mainstreaming students, rather than there being a shift in their ideological position towards meaningful inclusion for all. Therefore, the outcomes of this doctoral inquiry are incredibly timely, as the Government hopes to encourage more families to seek a mainstream education for their child or young person. Clearly, the education context that this inquiry was undertaken in was a challenging one for the mothers who took part in this research, which was reflected as we discussed our experiences.

5.2 Impact of the COVID-19 pandemic

COVID-19 was declared a global pandemic by the WHO[34] in March 2020, six months into this doctoral study. Although the global response to the pandemic led to ‘dramatic changes’ to our daily lives, for instance with the introduction of lockdowns, facemasks, and social distancing, the response within education was to maintain an experience that was as close as possible to the prevailing system, eg. pupils in schools often continued to have timetabled lessons and needed to submit work for assessment (Orchard et al., 2020).

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[34] The World Health Organisation

The University of Birmingham set out expectations that PhD students would ‘do their best to engage with their studies’ and should amend their research plans to ‘mitigate the disruptions to research as best they can’, with the option to submit a Statement on Disruption to Research to provide examiners some flexibility with respect to the quality and scope of the work produced[35]. Instead of submitting a Statement on Disruption to Research, I offer this short account to return to a time when ‘everything came to a stand-still. Life as we knew it was interrupted’ (D’Olimpio, in Orchard et al., 2020:5). In recounting my situated experiences here, I aim to make visible some of the struggle and tensions of undertaking a PhD during a global pandemic, whilst also recognising that the ongoing disruptions provided opportunities for new connections and a different way of engaging with academia, an account which can ‘(re)frame the pandemic as a somewhat generative event’ (Rutter et al., 2021:7).

In March 2020, to slow the spread of COVID-19, schools in England were required to close except for critical keyworkers’ children or pupils deemed as ‘vulnerable’, which included pupils with EHCPs (Beaton et al., 2021:394). Although my disabled daughter was entitled to be in school, she was also classified as ‘clinically extremely vulnerable’, so she was simultaneously required to ‘shield’ (HM Government, 2020:36). This meant that our family decided to completely isolate at home and avoid all face-to-face contact. During the

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[35] If the disruption to research could not be mitigated against, PhD students could apply for a short extension. I applied for the maximum six-month extension and was granted just three months. My research with mothers was delayed by approximately one year.

pandemic, disabled people faced additional obstacles to accessing healthcare and became subject to Do Not Attempt Cardiopulmonary Resuscitation notices[36] without consulting them or family members, who were unable to visit them in hospital or care settings. There was a disproportionate number of learning-disabled people who died from COVID-19, and there were heightened levels of anxiety for disabled people and their families (Tapper, 2021). This was particularly challenging, both mentally and emotionally, and I was frequently unable to focus on anything other than how best to protect my daughter.

As Norris (2020) describes, '[p]racticing philosophy while pandemic parenting is a tough fit' when 'childhood is exploding all around you in its most disruptive, messy, loud and enchanting manner'; it becomes impossible to 'read or write or think about anything substantial' (Norris, 2020:181-3). Philosophers aren't deemed as 'essential workers' even if we might 'need philosophy more than ever in a pandemic' (Norris, 2020:181), therefore my daughter's education and care became my priority. It has been well documented that mothers were in a disadvantaged position in the Academy during the pandemic (Sverdlik et al., 2022). Furthermore, female doctoral students 'experienced more negative academic emotions while engaging in academic work during the COVID-19 outbreak, such as anxiety, upset, and irritability, as compared to their male counterparts' (Sverdlik et al., 2022:11). For PhD researchers who were juggling parenting and home-schooling, there was a period of 'ongoing severe disruption to our working week, which no amount of methodological innovation could possibly mitigate' (Munro & Heath, 2021:34). This situation was even worse

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[36] It is suggested by Carter (2020) that this was due to confusing guidance from the Government in the context of the Health Service being overwhelmed. However, others such as Tapper (2021) have argued that it was fundamental discrimination, as learning disabled people were seen to have less value than others and were being written off or forgotten.

for those of us who have learning-disabled children, who needed even more support and protection during the lockdown periods than most typically developing children might need. I frequently felt pulled between my roles of home-educator and researcher, experiencing significant levels of guilt and a sense that I was not doing well enough at either role. As a mother of a disabled child, I know that I was not alone in frequently feeling like I was at 'breaking point' (Pearson, 2024:2).

It is also important to note that I knew any potential research participants were also facing a range of COVID-19 related challenges. As Pearson (2024:2) describes, parents of disabled children 'were experiencing a compounding set of experiences: the loss of the structure and therapies provided by school or other providers, the physical and mental pressures of now caring for their children full time, and the loss of respite care'. This meant that I felt unable to start the recruitment process until most children had returned to school and the Government had ruled out further school closures, as I did not want to add further pressure or emotional stress. Therefore, whilst ethical approval for my inquiry was submitted in May 2020 and approval was granted in September 2020, recruitment for this research inquiry did not commence until May 2021[37]. The empirical element of the research was also intended to only last approximately six months, however it took almost a year due to either me, my family or those involved in the inquiry or their children either catching COVID-19 and needing to self-isolate or facing additional school or pandemic related pressures that led to wider gaps between meeting-up than originally anticipated.

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[37] A delay of one year, though I received only a 3 month extension from the University of Birmingham.

Normative timelines for research 'do not allow for disruption, delay or dalliance' (Ulmer, 2017:201). However, it was impossible for me, as a mother with care-giving responsibilities to 'conduct business-as-usual in the wake of a global pandemic and maintain the same pace of productivity and engagement' as prior to the COVID-19 crisis I found myself in (Corbera et al., 2020:193). Ulmer (2017) describes how, rather than accelerating in a race against others to cross the PhD finish line[38], it is possible to explore collaborative opportunities that foster 'healthy, sustainable, productive, balanced, meaningful, and Slower – if not Slow – approaches to inquiry' through which we might come to 'view our own spaces differently and eventually find ourselves within the scholarly spaces in which we would want to work and play and live' (Ulmer, 2017:208). The pandemic forced me to slow down, and it highlighted how my identities as mother and PhD researcher were more entangled than ever before. Accordingly, I came to recognise that a 'slower way of scholarly being' was 'not unproductive, but… differently productive' and full of possibilities of producing research differently (Ulmer, 2017:201-2). It was during this period that I started to read posthuman theories and how they were applied in research inquiry, because reading short articles and book chapters was the only thing I really could find time to do in between my newly prescribed home-teaching responsibilities.

As Watermeyer et al (2021:624) claim, '[t]he societal impact of COVID-19 is almost incalculable'. Indeed, it is impossible to calculate or describe the full impact that the pandemic had on this inquiry, given that COVID-19 'took over, shifting established habits and

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[38] A race I could not win due to my caring responsibilities.

practices and catalyzing new ways of being, doing, and thinking' (Bozalek et al., 2021:844). I had reduced access to the library, fewer opportunities to gain additional graduate research or training opportunities, and a lack of sense of belonging to the department and School within my host institution due to less time spent on campus. The COVID-19 disruptions have therefore potentially put me at a disadvantage compared to those who completed their PhD before the pandemic, or those who had fewer caring responsibilities and who completed their doctoral research quicker than I have. Whilst I am grateful for the opportunities presented by the pandemic, such as the online reading groups I have discussed previously, as Rutter et al (2021) describe, there have been clear barriers to progress in PhD research and it is important that any positive account of the pandemic does not 'sugarcoat' the hardships that doctoral researchers have faced during the pandemic (Rutter et al., 2021:7). 2020 onwards was a particularly challenging time to be undertaking doctoral research as a mother of a disabled child.


DOESN'T ALWAYS LOOK LIKE ME."
"I WASN'T JUST AN ANGRY GIRL
I WAS FUCKING FURIOUS.
WHY
play
THE
GAME
SONG AND DANCE
MUM CRIED
During the darkest times
WOMAN ON THE EDGE
nothing to lose
SHE WAS WORRIED
Fed up
ignored
PULLED APART
FULL ASSAULT
THE SENSES
FROM DESPAIR TO WHERE?
THIS IS PERFECTLY ACCEPTABLE.
Journey for Life

5.3 Experience of SENDIST Tribunal

During this research process, I have also had to challenge the Hampshire County Council about a lack of Preparation for Adulthood educational provision for my daughter. As Strom (2021) describes, it is important to put our stories out into the world, even if they make us vulnerable by doing so. Strom, discussing a period of personal turmoil, describes how she experienced a ‘mind-body implosion’ that stopped her working in academia for what she refers to as a ‘lost year’ (Strom, 2021:2). Whilst I did not *lose* an entire year, the process of challenging the LA via SENDIST tribunal[39] had a considerable impact on my ability to work on this inquiry over a similar period. And yet, like the COVID-19 pandemic, whilst the experience was incredibly difficult for me, it was also generative for this inquiry.

Going to tribunal is both stressful and distressing for parents (Runswick-Cole, 2007; Cullen & Lindsay, 2019). Cullen & Lindsay (2019) describe how the lengthy process is intellectually demanding, LAs regularly fail to meet deadlines, and the way that parents are treated throughout the process by LA staff can be seen as both unpleasant and unprofessional. I had completely underestimated the emotional and physical impact that engaging in these processes would have on me. Whilst I managed to navigate the process without paying for professional reports or solicitors, so the financial cost was minimal, I lost the time spent on the process and it had a heavy toll on my emotional wellbeing. When waiting for an email response or a document to arrive by a specific deadline, I could not focus on anything else.

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[39] The First-Tier Special Educational Needs and Disability Tribunal (SENDIST) considers parents’ and young people’s appeals against the decisions of the Education Authority about special educational needs, where the parents cannot reach agreement with the Local Authority.

Constantly checking my phone or laptop to see if anything had arrived, knowing that they would miss deadlines but still hoping that we could resolve the ongoing conflict. Paralysed by worry. Unable to focus. Failing at being a good wife, mother, friend, or PhD researcher. At times I felt utterly broken.

Strom (2021:11) describes how during a 'lost year' the feelings in her body were so intense that they took over completely, she became 'a mass of sensation.' As a result of spiraling thoughts and intense bodily symptoms, she came to recognise how thoughts in the mind and feelings in the body are 'connected, entangled', not as separate entities but instead each 'producing the other, and amplifying the responses of the other' (Strom, 2021:16). She had gained 'embodied knowledge' and a heightened awareness of her body in a way she had not experienced before, teaching her about theory 'in a very different, embodied, way' rather than on a 'theoretical, intellectual level' (Strom, 2021:20-1). Apart from in the final month before the Tribunal hearing date, which was especially difficult, my feelings of paralysis were generally short-term and sporadic – often happening around a deadline or following a particularly unhelpful email from the LA. However, these experiences – along with the conversations I engaged in with parents taking part in this inquiry – similarly led me to know the importance of recognising the importance of paying attention to the body and its responses. This led me to read about affect theory in a way which, I believe, has more resonance now that I am not only engaging with the theory on an intellectual level but with my body as 'an ontological site of becoming' (Braidotti, 2022:113).

As Braidotti (2022:113) describes, there is a need to ‘acknowledge the embodiment of the brain and the embrainment of the body’. It is necessary to recognise our embodied subjectivity and our capacity to affect and be affected by others ‘in mutual interdependence’ (Braidotti, 2022:137). She further describes how ‘bodies are relational and affective’ which means that ‘they are capable of incorporating external influences and unfolding outward their own affects’ (Braidotti, 2022:113). As such, a focus on ‘real-life, embodied and embedded, relational and affective women’ (Braidotti, 2022:113) offers new implications and possibilities for thinking about the workings of power. This led me, within my research, to shift away from an original intention of exploring how discourses shape parental subjectivity. Whilst not wanting to dismiss the ‘importance of language, signification or meaning-making’ (Braidotti, 2022:110), my experiences of the Tribunal process helped me recognise that this alone is insufficient to incorporate in this inquiry.

My experiences have also made me even more determined to ensure that this inquiry makes a difference, both for the parents who were kind enough to volunteer to enter a conversation with me, and for other parents having to go navigate the SEND system. Parental advocacy is demanding, and you can often feel very alone. If nothing else, I hope that any other mothers of disabled children who are reading this will recognise that they are not alone and that it is possible to come out of the other side, and to get your strength back, even if it does not feel possible at the time.

6. METHODOLOGICAL APPROACH: CONVERSATION

6.1 Introduction

Thinking-together recognises that we are ‘beings-together-in-plurality’ in the world; it is a way of thinking that requires us to be open to re-examining our beliefs, values, interpretations, and ideas as we encounter others (O’Donnell, 2012:268). This is a different type of philosophical thinking that involves the ‘movement of thinking’ in the embodied presence of others, which can lead to ‘an unruly exchange of ideas’ and a ‘passionate liveliness of thinking’ that we could never have imagined alone (O’Donnell, 2012:270-4). A ‘richer ground’ can be found when allowing your views to ‘jangle, twingle and twangle with the views of others’ (Hodkinson et al., 2020:300). Within this approach it is important to ‘stop trying to own the positions of others’ or attempting to imagine the world from their perspective, rather it becomes necessary to allow experiences and viewpoints to emerge, collide and tangle in meandering wanderings (Hodkinson et al., 2020:300).

As mentioned previously, it was important to me to find or create a research approach that recognises both that mothers defy categorisation, and that ‘the process of becoming—or not yet being—forms an essential part of parents’ engagement with and resistance to a whole host of disability knowledges’ (Goodley, 2007:146). Having read Bojesen’s writing about conversation as research, based on Blanchot’s *Infinite Conversation* (Bojesen, 2019; 2020; 2020a; 2021), I came to the conclusion that this approach would provide an opportunity to experiment ‘with nonlinearity, zig-zag thinking’ (Braidotti, 2018). Conversation as a research approach enables ‘rhizomatic thinking’ as topics of conversation ‘branch out in multiple directions’ to create new connections and relations, with both the conversation and those engaged within it ‘changing as it goes’ (Colebrook, 2021:1-2). Conversation can embrace ‘more unsettled understandings of life and the world as multiplicities of relations and connections’ (Harrison et al., 2020:404). It offers an approach to inquiry that also resists any suggestion of there being a researcher who is an ‘always-already subject ready to capture and code the experiences of our participants and their material conditions as always-already object’ (Jackson & Mazzei, 2012:12).

Conversation as research does not attempt to ‘capture or describe what already exists but bring orientations of thought into being’ through ‘multiple movements’ between the parties engaged in the conversation (Colebrook, 2021:5). As Bojesen (2020) describes, ‘spaces of conversation might speak to us, interrupt us, and provoke our sense of insufficiency, as educational spaces’ (Bojesen, 2020:110). Conversation allows the creation of new understandings ‘as we relate to ourselves, to others, to the world around us in ever complex and shifting patterns’, because each ‘contact, encounter, or new piece of information can lead to new ways of attaching and detaching ourselves’ as we ‘develop new ways of seeing, interpreting, and thinking about ourselves: [in] what Deleuze and Guattari (2004) call “lines of becoming”’ (Ros i Solé et al., 2020:399).

6.2 The Qualities of Conversation

Conversation is ‘commonly conceived of as a casual talk between two or more people’ (Bojesen, 2019:650). Conversation ‘wanders, takes detours, and gets embroidered with the loose threads of life’ (Todd, cited in Henry & Heyes, 2022:5). A key to conversation is bringing together different voices, interruptions, and welcome meanderings, which takes time and mutual recognition (Furman, 2021:1353). Words in conversation move, ‘play off each other’, come together, in an ‘improvised rhythm’, in relation with one another (Manning & Massumi, 2014:118). Smock (1996:126) describes how:

> conversation isn’t, perhaps, anything at all that he says or she says or that they say, and even its characteristic movement—its back-and-forth, to-and-fro… but rather a function of their being neither one nor two. Conversation may be something like the pulse of their relation: together-apart; separate-joined; divided-united.

6.2.1 Emerging, moving, rippling…

Conversation can be seen as a ‘work in progress’, as something that ebbs and flows, continually added to with interplay between ideas that emerge in a shared space (Furman, 2021:1346). Importantly, one can enter a conversation with no agenda other than connecting with another (Furman, 2021:1345) or a ‘broadly stated intention to “hold space”’ for whatever thoughts and feelings might arise during the conversation (Pigott, 2020:881). It encourages an ‘expansive and generative’ mode of engagement, that offers a ‘starting point rather than an end goal’ (Henry & Heyes, 2022:6). Conversation here does not exist as ‘a back-and-forth between two separate bodies’, rather it is a ‘single relational flow occurring in complex relation’ where ‘[w]ords and gesture, tone and rhythm, fold generatively back into one another’ (Manning & Massumi, 2014:119). Although each party was engaged in the same event, they will each have ‘thought and felt differently’, and these thoughts and feelings will have an influence both on further conversations with each other, but also when they are apart, spreading ‘like ripples’ (Manning & Massumi, 2014:119).

6.2.2 Affective

Conversation has potential to affect, through the engagement with the 'flesh-and-blood realities of other people' (Henry & Heyes, 2022:8). As Henry & Heyes (2022:4) describe, the open-ness within conversation can respond to 'the unpredictability of living with others, in all its affective complexity'. Conversations 'tend to be informal and fluid', as the focus of the conversation shifts, with longer being spent on some topics, whilst some are dropped and potentially picked up again at some future point (Furman, 2021:1346). Importantly, within conversation, topics of interest are developed 'in a manner that is both individualized and pluralistic' (Bojesen, 2020a:39). Conversations are not neat and tidy, they can involve interruptions, pauses, fluidity in and between topics being discussed (Lipari, 2014).

6.2.3 A listening space

Conversations are also 'necessarily, a listening space' (Bojesen, 2020a:39). When we ordinarily think about listening, we usually think about hearing as a physiological process of perceiving sounds and our understanding and interpretation of those sounds (Lipari, 2014). However, as Lipari (2014) describes, this suggests the transmission model of communication, where ideas are moved from one brain to another, where what becomes important is the accuracy of the message and the precision of its reception. Within research encounters, this might suggest pre-prepared questions participants understand and respond to, or that a researcher has clearly understood the message the participant has attempted to convey. However, as Honan (2014:4) describes, this fails to capture the 'movement of the actors, the sounds of the voices, the background noises, and the discursive mappings through to other moments of time' emerging within and alongside the research assemblage.

6.2.4 More than words

When we listen, we are voices from the past, future and present come together in conversation, entangled in and between thousands of other conversations, an ensemble of spoken, unspoken and not-yet-spoken discourses that are meaning-making (Lipari, 2014). Conversation therefore allows for new possibilities and new becomings, as the 'I' becomes interrupted by 'complex emotional and contextual factors, histories and experiences that supersede our own limits and wants' (Henry & Heyes, 2022:5-6). Conversations never stand on their own, and each conversation 'includes an infinity of factors, other than language' (Manning & Massumi, 2014:119-120). We enter into conversation as part of a multiplicity, 'always collective and historical' (Kanngieser, 2020:unpaginated).

6.2.5 Transformative

Conversation has a 'transformational potential' that 'does not lie in utilitarian aims', rather 'more fundamentally in attending to the movement of thought in new ways... centred on practices of attentiveness and listening, thus making possible different relationships with ourselves, other people, and the worlds we inhabit (Pigott, 2020:881). It incorporates an approach to listening that holds a radical potential, through its 'relinquishment of knowing' (Kanngieser, 2020a:unpaginated). It provides an invitation to be vulnerable as researchers, to enter a research relationship of unknowing, driven by genuine curiosity and the possibility for discovery, a path forged together towards something new (Pigott, 2020; Gilligan & Eddy, 2021). Hodgson (2013:21) describes how conversation ‘is invoked as the necessary condition of our living together, predicated on listening and our answerability to the other’. This requires a mode of listening that opens oneself to the voice of others and their experiences, ‘tapping into the relational nature of human beings’ (Gilligan & Eddy, 2021:141). It is important to ensure that conversational spaces are not reduced to the logic of the institution, which can lead to a sterile space (Bojesen, 2020a:39). Instead, conversation should be recognised ‘as a creative, interpersonal act’ that requires ‘convivial and caring practices of speaking and listening – practices which may be unfamiliar and difficult, but which are necessary for learning to live better with complexity’ (Pigott, 2020:885).

6.3 Conversation as inquiry

Bojesen (2019:651) argues that ‘Blanchot’s formulation of conversation as plural speech, that exceeds dialogue and dialectic… offers a unique way of conceiving of educational research and of education as research’. He describes how ‘most philosophical research in education relies on a relatively fixed conception of the subject and knowledge’, whereas research undertaken through conversation as plural speech ‘does not reinforce the subject’ (Bojesen, 2019:651). This is because the developmental ‘movement of thought’ cannot be clearly attributed to ‘a secure and stable subject’, rather it is a process (Bojesen, 2019:651). The aim is neither to produce new knowledge that can be relied on scientifically, nor to form a subject, instead conversation seeks to deform and dissolve fixed and stable identities, putting subjectivity always on the move as parties lose themselves (Bojesen, 2019:652). As a result, as Bojesen describes, ‘spaces of conversation might speak to us, interrupt us, and provoke our sense of insufficiency, as educational spaces’ (Bojesen, 2020:110). Importantly, as Henry & Heyes (2022:8) further describe, ‘conversation puts identity at risk by moving beyond the desire to assert fixed positions, opinions or goals’, which is particularly important in any research inquiry that recognises subjectivity as becoming.

Approaching research through conversation recognises how both researcher and research participants are becoming as they are engaged in ‘creative, vibrant, embodied processes of transformation, which in the light of new experience and new connections, create new productive understandings – as if something is just caught in a different beam of light, altering its appearance, its meaning’ (Ros i Solé et al., 2020:400). This provides an alternative way of thinking about how to undertake research, enabling a ‘focus on the subject as multiplicity, as process and on a pre-individual subjectivity, a subjectivity that is open to the vital force that allows the subject to decentre’ (Ros i Solé et al., 2020:398). Therefore, by utilising conversation within this inquiry, I have been able to move away from the humanist model of education ‘that requires a relatively stable conception of “subject” and “knowledge”’, by embracing the movement of thought and ‘deprioritising individual linear development’ and forms of education predicated on ‘growth, accumulation, and production’ (Bojesen, 2020:121).

Conversation creates an educational research encounter that is full of possibility (Ros i Solé et al., 2020:398), opening ‘towards something which does not yet exist and, unlike overly structured educational practice, cannot be predetermined' (Bojesen, 2020:109). Conversation can therefore provide a 'gift of encounter' offering the opportunity to 'to be transformed, to transgress boundaries, to become someone/something else' through a 'meeting with unknown possibilities' (Taylor et al., 2022:18). It offers a way of 'producing knowledge otherwise' that 'offers a critical push back against extractive (masculinist, colonialist) knowledge logics (push and pull, smash and grab, hit and run)' (Taylor et al., 2022:16-17). The outputs from conversation are 'generative rather than representational material' (Pyrry, 2022:67). Through wandering and wondering with someone who is 'other' than me, there is a 'dwelling with' and an opening 'toward the 'other'' in an active engagement with the world (Pyrry, 2022:70).


become
In conversation
WHERE LIFE UNFOLDS
to create energetic landscapes.
planting out seedlings, digging up new potatoes.
space to sketch out plans and to record how things actually turned out.
We need to start having conversations
evolving
RECREATING
In it together
INTENSIVE CARE
incorporated
Mother
strong women
MAKING
Time for what matters
RIGHT HERE, RIGHT NOW.
New tunes from a hatful of old songs
places that nurture.
inspiration gleaned
planted the seed
"WE'VE BROKEN OUT OF ABSOLUTES AND RULES"
assumptions we use to make sense of the world do not exist, like Tupperware boxes, as fixed, closed structures able to be neatly stacked
ALL THE CHARACTERS GROW AS THEY FACE THEIR OWN OBSTACLES AND DILEMMAS
love
Life
in flux
constantly shifting
a world of
colour and shade

6.4 Conversation with mothers of disabled children

Fisher & Goodley (2007) argue that it is necessary to move away from a linear narrative when undertaking research with parents of disabled children. They contend that linear narratives can lead to a construction of disability based on a medical framework, with a focus on future development and progression. Such a linear narrative aims for certainty in a way that is ’restrictive and liable to block the development of alternative thinking as well as the imagining of more empowering ways of being’ (Fisher and Goodley, 2007:68). Instead, they argue it is necessary to recognise how mothers of disabled children frequently construct alternative narratives that challenge the notion of linearity as they embrace uncertainty and have a sense of hopefulness about the future (Fisher & Goodley, 2007:68-72). Fisher & Goodley employ a conversational approach in their interviews, where the direction of the discussion is left in the hands of the parent being interviewed (Fisher & Goodley, 2007:69). They describe how this allows knowledge to be co-produced within a relational process, embracing ‘pure difference’ and ‘the very resistant and flighty nature of becomings’ (Fisher & Goodley, 2007:77-8).

Rather than a conversational approach within an interview, this inquiry explicitly positions itself as different to a traditional interview. There were no pre-prepared questions nor data to be collected (Honan, 2014). The research conversations were based on ‘everyday talk’, the ordinary kinds of casual communication that mothers might engage in, within the playground, at home with friends or when visiting a café or support group (Kohl & McCutcheon, 2015). Kohl & McCutcheon (2015:749-750) argue there are benefits to engaging in ‘kitchen table reflexivity’, where it is possible to develop a meaningful interaction in informal conversation that is both cathartic and allows discussion of the topic in nuanced ways. Conversation and kitchen table reflexivity can provide space within which it becomes possible to ‘work through the messy and fluid negotiated relationships with research participants’, to develop a richer and more nuanced engagement with positionality and subjectivity that challenges the notion of insider/outsider and recognises the importance of attending to the ‘betweenness’ and fluidity in the research process (Kohl & McCutcheon, 2015:752-3).

As Ruddick (1995:25) describes, mothers ‘meeting together at their jobs, in playgrounds or over coffee can be heard thinking’. Mothers often reflect on their mothering practice and will often engage in conversation with other mothers as part of this (Ruddick, 1995). Accordingly, it is necessary to pay attention and respectfully listen to ‘maternal thinking’ a form of philosophising about the world that has ‘been drowned by professional theory’ (Ruddick, 1995:40). This thinking is ‘not voices of mothers as they are, but as they are becoming’ (Ruddick, 1995:40), a subjugated knowledge and form of thinking that arises out of the singularities of maternal life and the concrete conditions within which it is undertaken (Ruddick, 1995). This type of knowledge and thinking is particularly important to engage with when undertaking research with mothers of disabled children. As Runswick-Cole et al. (2022:322) describe mothers of disabled children:

> are engaged in everyday theorising about the lives of their children as they navigate the often hostile waters of education, health and social care. And while some philosophers become mothers of disabled children (Kittay, 2019), all mothers of disabled children become philosophers.

It is important to think about how knowledges and practices are developed through the everyday encounters we experience, and conversation as inquiry is a way to engage in such meaning-making (Harrison et al., 2020). By carving out ‘deliberate spaces’ which offer opportunities to ‘chew the fat’ together (Harrison et al., 2020:408) my intention is to draw on the maternal knowledge and expertise of mothers of disabled children that can so often be overlooked or dismissed as irrational or just feelings. I decided to arrange one-to-one conversations with the mothers taking part in this inquiry, rather than focus group discussions. I am aware from my engagement with SEND-related social media platforms and within coffee morning or support group meetings, that some voices or positions can come to dominate. I did not want to limit the flow or direction of where the conversations might go, so this felt a more appropriate route to allow for a range of diverse opinions and experiences to be discussed and then brought together.

7. PRACTICAL ASPECTS OF THIS RESEARCH INQUIRY

7.1 Ethics

Ethical approval for this study was granted by the University of Birmingham Ethics Committee (ERN_20-0641) on 18 September 2020. The ethics application and approval letter can be found in Appendices Two and Three.

The following appendices also formed part of the ethics application:

- Appendix Four – participant information document
- Appendix Five –my commitment/participant consent form
- Appendix Six – approved data management plan

Research is generally conducted within an ethical framework that 'prioritises non-maleficence (doing no harm, primum non nocere) and leans strongly towards the universal application of Western ethical principles' (Vermeylen & Clark, 2017:503). Protection from harm is 'assumed to follow unproblematically' following the initial ethical approval (Vermeylen & Clark, 2017:503). However, a broader engagement with what it means to be an ethical researcher is crucial to this inquiry. I do not wish to perpetuate any further oppression or marginalisation of disabled people or their families, therefore I pay close attention both to procedural ethics and 'ethics in practice', that is the 'ethical encounters that can arise unexpectedly during the course of the research' (Ribenfors, 2020:230-1). Every aspect of the research design and implementation has ethical implications (Ribenfors, 2020) and I have taken this responsibility seriously.

I draw on the work of Levinas to discuss a broader approach to ethics, having been introduced to his theories when undertaking undergraduate studies (Smith, 2020). Levinas's ethics is underpinned by his famous assertion that ethics is 'first philosophy', whereby what it is to be human must begin with ethics (Putnam, 2008:70). For Levinas, to be a human it is necessary to obey the fundamental ethical command, which is to make ourselves available to the 'Other', to meet our 'infinite' responsibility and obligation to them (Putnam, 2008:75-6,80). He positions ethics as 'prior to ontology or epistemology', rather than seeing ethics as a practice that is secondary to knowledge (Gehrke, 2010:6). Levinas was critical of how there is a 'primacy of the same' within traditional Western philosophy (Levinas, 1969:43), by which he suggests that we can never know other people fully due to the limits of our own understandings. This can result in another person's absolute difference or otherness becoming absorbed into our 'own identity as a thinker or possessor' (Levinas, 1969:33). As Todd (2001:73) describes, the Other becomes an object of 'my comprehension, my world, my narrative'.

This ethical approach also heavily influenced my choice of conversation as a methodology. Blanchot (1993:215) contends that plural speech 'is a speech that is essentially non-dialectical; it says the absolutely other that can never be reduced to the same'. Therefore, it recognises the limits of our understanding of others, which can only ever be reduced to our own experiences or understanding. Given that this inquiry was specifically designed to 'approach' rather than 'understand' the subjectivity of parents, utilising conversation allows the inquiry to be undertaken with an 'intense curiosity' alongside a recognition that research participants can only ever remain 'a kind of mystery' to me (Allan, 2011:160).

Levinas's ethical approach can also be seen to encourage affirmative practices within research that put the wellbeing and alterity of research participants at the 'heart of research' (Vermeylen & Clark, 2017:503), something that I specifically wanted to do. Levinas describes the ethical relation as the original 'After you, sir!', where we put the other person's interests before our own (Levinas, 1985:89). Instead of adhering to abstract rules, we must recognise what we are 'called on' to do in the moment, to respect the 'alterity' of the Other in their 'manifold difference' (Putnam, 2008:95). To be able to do this, I need therefore to 'accept the inevitability of uncertainty', as it is not possible to rely on established solutions or tricks of the trade (Allan, 2011:160), rather I need to find the most ethical and affirmative way to respond within each encounter. As Rhodes & Carlsen (2018:1297) describe, this approach requires an 'ethical vulnerability', where my 'own knowledge and self-understanding are themselves open to question through the research encounter'. Through the conversations with other mothers in the inquiry call both my subjectivity and my understandings into constant question (Garza & Landrum, 2010). I needed to be willing to be personally affected and changed through my interactions with them, rather than attempting to classify or compare them according to my existing framework of knowledge (Rhodes & Carlsen, 2018:1297). Rhodes & Carlsen (2018:1298) describe how this does not position me, as the researcher, in a 'sacrificial position', rather it should lead to a 'heightened sense of meaning in research' as it becomes possible to pursue 'wonder' in an 'unpossessive and emphatic stretching towards the other'.

Instead of approaching the world, subjects or knowledge as something 'inert, still, able to be captured and known – mastered' (St. Pierre, 2023:25), this inquiry engages with maternal subjectivity as 'multiple, entangled, ever-shifting, difference-rich' (Strom et al., 2020:2). As

Taylor (2018) describes, within this ontological and epistemological approach, ‘ethical considerations become a matter of relations, engagements, and entanglements, and ethical relations become materialised in and through activations, attunements and instantiations’ (Taylor, 2018:81). Although Levinas is a humanist theorist, his ethical approach is not completely inconsistent with the philosophical underpinnings of this inquiry. Indeed, Calarco (2019:71-2) suggests that in Levinas’s work we ‘encounter a fundamentally relational account of human existence’ and that Levinas’s work might also be considered posthumanist in orientation.

St. Pierre describes how the relation of responsibility means that I am always ‘responsible, everywhere, all the time’ (St. Pierre, 1997:177). This entails relations of responsibility, rather than compliance with a set of pre-determined values or rules of action, which are designed to be relied on to guide researchers in ethical quandaries (St. Pierre, 2013:149). An ‘ethics of response’ cannot be defined in advance for all situations, instead it is ‘invented in each relation as researcher and respondent negotiate sense-making’ (St. Pierre, 1997:186). Braidotti (2013b:342) suggests an affirmative and relational ethical approach is needed that ‘looks for the ways in which otherness prompts, mobilises and allows for flows of affirmation of values and forces which are not yet sustained by the current conditions.’ Both align with Levinas’s ethics. Becoming-responsible-with requires me to both attend and respond (Albin-Clark et al., 2021). To be attentive, it is necessary to create spaces to learn from and with others and to notice what is happening, to notice who is being silenced and marginalised, which might be discomforting (Albin-Clark et al., 2021:22,27). To respond it becomes necessary to do something with what I have noticed, to explore potentialities with an orientation to the future, to care, to collaborate, to ‘build doings that are affirmative, ethical, dynamic and multiplying’ (Albin-Clark et al., 2021:28).

My intention throughout has been ‘to think with, rather than for’ (Strom et al., 2020:28-9) the mothers engaged in this inquiry. I have therefore attempted to be open to allowing the ‘affective force’ of relational encounters in conversation to ‘stick’ to me in an ‘embodied knowing-otherwise’ (Strom & Mills, 2024:668). By which I mean that there are phrases mentioned or experiences that were discussed that have stayed with me[40], which I think about even when not engaged in research, that have influenced how I think about inclusion or have pushed me to read and theorise about a particular topic[41]. The conversations that I engaged within live within me and continue to affect my way of engaging in the world both as researcher and as my daughter’s advocate. Sometimes these affects cannot be articulated easily though, they are just felt in my body.

An affirmative ethical approach necessitates a move beyond identity categories, which can capture and pin individuals into specific locations of power, instead moving towards a more affirmative way of being in the world with each other (Braidotti, 2018). To pursue an ethics of affirmation requires us to be confronted by and to map out the conditions that shape our existence and that disempower us, but then to be the ‘stubborn counterpoint’ that kicks it in the face and says ‘Yes, but we are in the process of becoming something else’ (Braidotti, 2019:471-2).

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[40] On my way home from my first meeting with Faith, I missed my turning on a roundabout twice when thinking about a particular aspect of our conversation, where she described how Brave was just wanting to be accepted and loved by his teachers and not to be seen as a problem.
[41] I discuss this further in Chapter Eight when discussing the approach to analysis.

7.2 Recruitment criteria

When considering the recruitment criteria for this inquiry, I wanted to avoid making any claims about mothers engaging in this inquiry and as previously discussed, I did not want to be using problematic labels such as 'Special Educational Needs' or other language based on a deficit/medical model of disability. Several options were open to me, which I discuss below, alongside some concerns I have about each:

Potential recruitment criteria	Concerns
Any parent/carer of a child labelled/diagnosed as disabled or having Special Educational Needs/Disabilities (SEND)	The term 'Special Educational Needs' is based on deficit/medical model thinking, which I wish to avoid. I do not want to reduce either children/young people or their parents to their 'needs' when I refer to them. There is no clear definition that determines who does/does not have SEND. As Hutchinson (2020:15) describes, SEND support can be a postcode lottery and a range of factors will contribute to whether or not a child is labelled as having SEND, and also the categorisation is fluid with some children moving in and out of the label at various times in their education career. The school the child attends appears to be the biggest contributory factor as to whether they will be labelled, rather than the child's individual characteristics. This makes this criteria subject to professional opinion. Only children/young people with an Education, Health & Care plan (EHCP) can state a preference for mainstream or

	specialist education settings. Therefore, most children labelled as having SEND will be in mainstream education. As this inquiry aims to explore the choices parents make or think are possible re an education setting, there needed to be a narrower category than simply the SEND label.
Any parent/carer of a child who has an EHCP and therefore is able to state a preference for mainstream or specialist education settings	To have an EHCP, the child or young person needs to have ‘Special Educational Needs’ that require ‘Special Educational Provision’ to be made for them that is not normally available within a mainstream education setting. Again the reliance on the language and categorisation of ‘Special Educational Needs’ is problematic due to how it is based on deficit/medical model thinking. The EHCP process is long and complex, taking at least 20 weeks, if not longer. The final decision about the placement/type of placement is made by an education professional, although parents/carers and young people can state a preference. Holding an EHCP naming a particular type of setting might also be contingent on the parent/carer or young person having to appeal via Tribunal, which can be a costly, emotional and time consuming process too (as I discussed in Chapter Five). The EHCP process and appeals process is not equally accessible to all parents, for instance those who might have learning disabilities themselves or where English is not their first language. I therefore did not want to use having an EHCP as the criteria for engaging in this inquiry.

Parents of children/young people being educated in a particular type of setting (ie either mainstream or specialist)	I wanted to capture a broad range of experiences and understandings of what it means to be included, rather than from only one perspective or type of experience.

None of these potential approaches seemed to work so I went back to the drawing board. As a parent of a daughter with Down syndrome, I am aware that most children with Down syndrome do have an EHCP either before or as they start school, meaning that parents have been able to state a preference for a type of setting or a particular setting during the process. I also know that some children who have Down syndrome go to mainstream school, others are in specialist placements, and some have mixed placements where they spend time in both types of setting. This meant that if I used the medical diagnosis of Down syndrome as part of the recruitment criteria this would enable me to avoid using the language of special educational needs or the criteria of an EHCP, whilst still being likely to attract parents who were able to explore a range of experiences and options and state preferences for a type of education setting for their child. This is the option I chose.

It is important, at this juncture, to recognise that Down syndrome as a medical diagnosis is not ‘value-free’ (Ho, 2004:89). Diagnoses can also be seen as social constructs that are ‘highly contingent’, reflecting ‘the medical and social attitudes of a particular society in a specific era’ (Ho, 2004:89). Hacking (1986:163) describes how distinctions between people are made through scientific ‘discovery’ through which ‘new realities effectively came into being’. He describes how a category and the people in it emerge ‘hand in hand’ changing the ‘space of possibilities for personhood’ (Hacking, 1986:165). Further, as Ho (2004:89) describes, whilst diagnoses can be helpful in some cases, ‘in other cases they are intentionally or unintentionally used as a political tool to discriminate against students who are diagnosed of various impairments and to control their future educational and employment opportunities’.

Hacking (1986:168) describes how each category of people being made up has its own history, often with a ‘labelling from above, from a community of experts who create a “reality”’. There is a long and troubling history of people with intellectual disabilities being dehumanised and treated as non-human (Carlson, 2023). The genetic condition, which later came to be known as Down syndrome (or Down’s Syndrome) was first identified by Dr John Langdon Down, who ‘drew upon racist hierarchies and “apish characteristics”’ to connect mongolism and ‘feeblemindedness’ (Carlson, 2023:53). Cited in Dunn (1991), Langdon Down (1866) stated:

> I have for some time had my attention directed to the possibility of making a classification of the feeble-minded, by arranging them around various ethnic standards.
>
> The great Mongolian family has numerous representatives, and it is to this division, I wish, in this paper, to call special attention. A very large number of congenital idiots are typical Mongols. So marked is this, that when placed side by side, it is difficult to believe that the specimens compared are not children of the same parents. The number of idiots who arrange themselves around the Mongolian type is so great, and they present such a close resemblance to one another in mental power, that I shall describe an idiot member of this racial division, selected from the large number that have fallen under my observation.

Langdon Down hypothesised that ‘many forms of idiocy were in fact genetic throwbacks, avatars of earlier, less evolved races’ (McDonagh, 2008:270). As Jarrett (2020:213) describes, for Langdon Down it was ‘a perfect merger of race and mental capacity’ as ‘the five races of the world came together in the idiot population and were slowly civilized by the asylum, a microcosm of the colonial system’. It should be noted, of course, that Down’s ideas did not ‘come out of nowhere’ and Down was ‘professionally embedded’ in a series of current discourses (Chen, 2016:239). The phrase ‘mongoloid idiocy’ brought together the contemporary studies of race and idiocy (Chen, 2016:238). For Langdon Down, the ‘stagnated Mongol race of faded glory… atavistically erupted in the bodies of white children’ meaning that race was an ‘implicit and yet constitutive presence’ in the children’s developmental disabilities (Chen, 2016:238).

In 1959, Lejeune discovered that the condition was due to trisomy 21, a presence of 47 chromosomes rather than the usual 46 (Smith, 2011). It is important to recognise that Langdon Down’s conclusions arose due to the context he was operating within, just seven years after Darwin’s Origin of Species was published (Smith, 2011). It was a time when genetic racism and eugenics thinking was more palatable (Smith, 2011). However, as Smith (2011:7) describes, the legacies of the Victorian era continue to ‘live on in cultural echoes… leaving us with stereotypes that engender isolation and exclusion, of misunderstanding and stigmatization’. Even if the description of mongolism is declining in use, we are not yet free of the idea that ‘people with Down syndrome are fundamentally like each other and unlike us’ (Estreich, 2011:196).

As well as this inherited historical legacy, people who have Down syndrome are also constituted and produced through social and cultural artefacts, for instance within advertising or the media (Smith & Smith, 2021). Whilst people who have Down syndrome are generally no longer housed in institutions, ‘their inclusion in culture and society remains limited’ (Smith & Smith, 2021:289). Whilst people with Down syndrome might increasingly feature in advertising campaigns or popular TV shows, we rarely hear their voices and opinions (Smith & Smith, 2021). Accordingly, stereotypes persist and remain unchallenged – whether stereotypes of suffering, vulnerability or dependence, the image of eternally happy children, or projections of superheroes with magic powers to transform the lives of those who meet them (Smith & Smith, 2021), these stereotypes take on a life of their own. Thomas (2021:697) describes how parents of children who have Down syndrome attempt to ‘undo hurtful stereotypes in public forums, for instance, by registering their child with modeling agencies, appearing on television programs, and producing/sharing positive stories on social media and blogs’. Some of the parents in Thomas’s study were concerned about people who have Down syndrome being used for commercial advantage or as a tokenistic diversity ‘tickbox’ (Thomas, 2021). People who have Down syndrome rarely appear as ‘multidimensional, active citizens with their own experiences and life stories’ (Vertoont, cited in Thomas, 2021:700).

Whilst Down syndrome is a genetic condition, there are also historical, social and cultural accounts that shape how people respond to those with the condition and what futures are imagined to be possible. For example, as Chen (2016:246) stresses, children who have Down syndrome ‘are not imaginable as anything other than the subjects of their parents, not the future parents of others’. It is therefore necessary to recognise both the problematic history and the current cultural representations relating to people who have Down syndrome, and how these come to intra-act (Barad, 2007) to produce people with Down syndrome, and the impact that this can have, including in and beyond the classroom. However, I believe that using a medical diagnosis for the recruitment criteria continues to be less problematic than using deficit based definitions relating to Special Educational Needs or relying on the possession of an EHCP for the reasons stated in the table above. Down syndrome is the most prevalent genetic condition, and one where most children born with the condition will live well into adulthood. Pupils who have Down syndrome can also be seen to attend both mainstream or specialist education settings. It should be recognised, therefore, that the use of Down syndrome in the recruitment criteria for parents in this inquiry was a pragmatic decision but not an unproblematic one that is without critique.

7.3 Recruitment process

Recruitment for the inquiry commenced in June 2021, almost a year later than I had hoped. To enable some face to face meetings during the ongoing COVID-19 restrictions, which were ever-changing at this point, I decided to focus on geographical areas that were within a one-hour drive from my home so that I could avoid travelling distances that would require stopping in busy service stations or overnight stays away from home. I used an internet search to find the contact details for a range of organisations who I hoped might be able to share information about the inquiry, for instance:

- Special schools

- Down syndrome support groups
- Pan-disability support groups
- Parent carer forums

A copy of the email introduction to these gatekeepers is available in Appendix Seven.

I also posted on two UK based online Down syndrome support groups on Facebook, with explicit permission of the page owners. I used a slightly adapted wording as my email introduction but added an additional requirement that those who were taking part in the inquiry should ideally be no further than one hour from North Hampshire, and that they should not have any existing relationship with me. I did not want either myself or the parents engaged in the research to enter the conversations with existing knowledge about our personal situations or family lives. Although I asked people to privately message or email me, several parents responded asking for information about the inquiry on the post. As part of my ethical commitment to maintaining anonymity I deleted these Facebook posts once I had received initial interest.

7.4 Participants

More than twenty mothers contacted me requesting further information about the inquiry, stating that they might be interested in taking part. Although I cannot be certain how they found out about the inquiry, I believe most were from the social media posts given their geographical locations. Following their initial contact stating interest in participating, I sent out the information sheet and consent form to them via email[42]. I asked them not to sign the form yet, as I wanted to offer the opportunity for an initial discussion by telephone before they agreed to sign the consent form. This initial telephone call was incorporated into the recruitment process as I wanted to be able to discuss why I wanted to undertake this inquiry, to be able to answer any questions they had, and to discuss any access requirements before they agreed to take part. As a participant in many research inquiries myself, I would have welcomed this opportunity to engage with the researchers before signing a consent form.

Eight mothers responded positively following receipt of the information sheet and commitment/consent form, stating that they would like to take part in the inquiry. I therefore arranged telephone conversations with them. I used a prompt sheet for these telephone calls[43], none of which lasted longer than 30 minutes. These initial telephone calls were not recorded, although I did take handwritten notes with each mother’s explicit verbal permission. As these telephone conversations were prior to the consent form being signed and returned, they do not form part of the research data. All eight mothers signed and returned the consent form. However, one then chose to withdraw before the first meeting, which she said she felt sad about, stating that on reflection she did not feel she could commit the time to the project, which she felt would be a significant call on her time and she was shortly changing her job.

Five of the seven remaining mothers who agreed to take part lived within 60-90 minutes of my home, across five different LA areas, and two were in the North of England, in two

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[42] See appendices Three and Four
[43] See Appendix Eight

different LA areas. The research inquiry for the latter two was all undertaken remotely via video calls and emails, whereas I met all the five parents who lived locally at least once face to face and had additional video/telephone conversations and email correspondence with them all.

7.5 Shared agreement rather than one-way consent

Based on my experiences as a research participant I wanted think differently about the participant consent form, to generate a more affirmative and ethical practice when seeking consent from the mothers taking part in the inquiry. The standard approach to a consent form separates out the roles of researcher and participants. The researcher seeks the consent of the participants to use their data in their study. The participant consents to how their data will be gathered, recorded, stored, and used. They also are likely to confirm that they understand what the study will involve, and that they have had the opportunity to ask any questions. Bryman (2016) describes how the ‘advantage of such forms is that they give respondents the opportunity to be fully informed of the nature of the research and the implications of their participation at the outset. Further, the researcher has assigned record of consent if any concerns are subsequently raised by participants or others (Bryman, 2016:131). However, within a research inquiry that is based on undirected and open-ended conversation, it is difficult to set out in advance what commitment might be required of the participants, or for all their concerns and questions to be raised at the outset.

Also, the standard approach to seeking consent, positions the roles of researcher and participant 'as mutually exclusive' separating out a researcher who 'define[s] the project and contribute[s] all of the thinking towards the end result' and research participants 'whose actions and words are to be studied' by the researcher (Connor et al. 2018:407). This neat separation cannot exist within a conversation as research approach that has been used within this inquiry, as both myself and the parents are equally involved in producing the conversation and the movement of thought.

I also felt uncomfortable that the first formal aspect of the research inquiry relationship was the mothers giving me their commitment and agreement to take part in the inquiry, something that could only be completely unknown at that point in time, without me giving them anything in return. I therefore decided to write my own commitment to the mothers who would be taking part in the inquiry. This commitment was positioned prior to the section of the document that asked mothers to confirm their consent to be involved. It was important to me that it was this way round, as I did not want them to give me their consent without first having read my commitment to them. Once they had signed and returned the consent form, I co-signed it and sent back a copy to keep. This act of also signing the consent form felt important, to demonstrate that this was a collaborative and shared process, that was ongoing. As Bhattacharya (2007:1101) describes, consent forms can only serve 'as a fluid guideline rather than a blueprint of our relationship'. I wanted the form that mothers signed to have additional detail about how I wanted to approach that relationship, rather than just asking for consent to use their data. The signing of this form signified the start of the research process and our relationship, and I did not want it to simply be a tick-box or one-way exercise.

As mentioned above, although this consent form included elements that would be required by the institutional ethics board, such as confidentiality and keeping data protected, I also added in extra commitments that were my commitments to the parents, which did not require reciprocation. Here are two of my commitments that I felt were particularly important to include:

- Meetings and any agreed telephone/video conversations will be arranged for a time and location that suits you. I will check with you on the day to ensure that it is still convenient, as I know how life with a disabled child can sometimes throw curveballs your way! The conversation will fit in with your life, rather than my requirements as a researcher.
- I commit to using this research to explore new ways of thinking - I am not going into this study with any pre-conceived ideas about what the study should or will find out about parents, disabled children, or inclusion in education. However, I am driven by a desire to find new ways of thinking about the role of parents in relation to the inclusion of disabled children. I hope to achieve this by engaging with other parents of disabled children in a conversation about their experiences, what has influenced their thinking, and how things could potentially be done or thought about differently, in order to improve the inclusion of disabled children in education. I commit to sharing the findings of the research in wide and varied ways.

The full commitment and consent form is available in Appendix Five.

7.6 Anonymity and pseudonyms

Within this thesis and any outputs associated with this research inquiry pseudonyms have been used, as per standard research practice. The use of pseudonyms was built into my research ethics submission to ensure parents' privacy and anonymity, hopefully meaning that those taking part could feel confident that they could speak freely, without any risk or repercussion. It was anticipated that mothers might want to talk about relationships with professionals or challenges that they had faced, and they may have been unwilling to do so if they could be identified. It is also important to note that all the mothers who took part in this research inquiry have children with Down syndrome. Although they live in different geographical locations, there is a chance that they may know or know of each other through local or national Down syndrome training, events or social media. The use of pseudonyms has therefore further protected their identities with other parents of children who have Down syndrome.

As BERA describes in their *Ethical Guidelines for Educational Research*, '[t]he confidential and anonymous treatment of participants' data is considered the norm for the conduct of research' (BERA, 2018:21). Researchers should recognise participants' rights to privacy and accord them both confidentiality and anonymity (BERA, 2018:21). This default position is 'born from the assumption that "naming is dangerous"' and therefore anonymisation is required to protect research participants 'from harm' if they were to be identified (Gerrard, 2021:688). It also extends to protecting others, eg. family members, who could be identified by association (BERA, 2018). Whilst this research has not been undertaken directly with children who have Down syndrome or their siblings, their parents have discussed their educational experiences and these children/young people have not consented to having their identities made known within this research. Ensuring anonymity of the parents also means that their child/ren will remain anonymous. It needs to be recognised that complete anonymity can never be guaranteed and using a pseudonym or changing other identifying details is only part of a ‘more nuanced process’ (Saunders et al., 2015:617). For example, it is possible that those who took part in the inquiry might mention to others that they were a participant or might recognise each other’s words or stories if they have previously been told in public spaces such as Down syndrome support groups.

Saunders et al. (2015:630) describe how ‘anonymising is very much an evolving exercise that continues to throw up challenges and surprises’. Within this inquiry, I faced a challenge about anonymity and pseudonyms early in the process. The mother who withdrew from the research before it had commenced had mentioned how she was not comfortable with ‘hiding behind’ a pseudonym because she was proud of her son and the education and support that he had received. I recall feeling disappointed that I had not realised that some parents might feel strongly about using their own name and that this had not been originally factored within the ethics submission. After all, I am very aware of how parents feel disrespected when professionals do not use their names, when mothers of disabled children, are reduced to ‘mum’, and our own name is taken away from us. Names are important to people. As Lahman et al. (2022:2) describe, naming ‘can be both an act of validation and an act of disrespect’. Parents of disabled children frequently feel strongly about being called by their name, so much so that various campaigns have been launched to this effect, eg. the

‘HelloMyNameIs’ badge campaign, which was adopted by parents who felt like they were ‘disappearing’ when professionals did not use their name (Grant, 2021).

Image 6: Campaign logo

Brear (2018:724) describes how participants can ‘perceive being named integral to having a “voice”’. Non-anonymity can be seen to empower participants (Vainio, 2012:686). Whilst recognising the need to protect and safeguard the mothers who took part in the inquiry, it is also important to recognise that some might want to be mentioned by name, and it could be a way of amplifying their voice if this were to happen (Vainio, 2012; Gerrard, 2021; Kara, 2022). Following my conversation with the mother who felt uncomfortable about using pseudonyms, I spoke with everyone else taking part in the study, letting them know that if they preferred to use their own name then I would go back to the ethics committee to seek approval for this. Nobody asked me to do so, indeed one mother said her name was too distinctive and she preferred to use a pseudonym, and therefore pseudonyms have continued to be used throughout. As Saunders et al. (2015:618) describe, when given the option, some participants in research will ‘still wish their identities to be concealed’, as was the case in this inquiry. Saunders et al. (2015) argue it is necessary for contextually-contingent approaches to anonymisation. It is important that participants are invited to ‘engage in “careful deliberations” about the use and choice of pseudonyms’ (Brear, 2018:724), allowing them to understand the pros and cons of each option for anonymity (Kara, 2022).

It is also important to note that ‘naming is an act that can be imposed upon others but can also be used by someone to claim, reclaim, and empower themselves (Lahman et al., 2022:1-2). The pseudonyms used in this thesis have been chosen by the parents taking part in the inquiry, because I recognised that pseudonyms can present ‘powerful messages’ about personal identity characteristics such as ethnicity, race, faith or class (Vainio, 2012:693) and also, I recalled strongly disliking pseudonyms that a researcher chose for me and my daughter. The mothers have therefore also supplied a pseudonym for their child/ren and spouses too. One of the participants – Faith - chose this pseudonym part way through our conversation, as we spoke about the challenges that she was facing securing a suitable education for her son. It was a name that spoke to her journey and of the qualities she felt she needed to have to continue in challenging circumstances.

Although I drew on my own experiences as a research participant[44], which led me to the decision that parents should choose their own pseudonym, I should have considered that some might not want a pseudonym at all, considered the disempowering effects of not using a person’s actual name and furthermore what the implications of choices around naming might be for their child’s anonymity and rights to privacy. As Brear (2018:737) states, ‘[i]nviting participants to select their own pseudonyms or use their own names, without

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[44] As previously discussed in Chapter Four

providing specific opportunities to deliberate the implications, is insufficient' and there needs to be greater critical reflection.

7.7 Voluntary participation

Participation in this study was voluntary and unpaid. I gifted a box of Numicon[45] to one parent, which we no longer needed and when we tried to give it back to the charity that lent it to us, they asked us to pass it on to someone else who could use it. Otherwise, apart from the purchase of drinks when meeting in a coffee shop, the mothers engaged in the inquiry did not receive any material benefits.

Participants were advised that they could withdraw from the study at any point during the ongoing conversations or within three months of the final conversation. None of the seven mothers who signed the consent form chose to subsequently withdraw from the study.
In advance of the research inquiry starting, I prepared a document listing national and local support organisations, should any parent require signposting. The template that I designed and used for this is in Appendix Nine. I provided a copy of this to two of the mothers who asked for suggestions for local support organisations.

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[45] Numicon is an approach to teaching maths that helps children to see connections between numbers. It consists of plastic shapes with holes in that can be used to visualise the relationship between numbers and to undertake calculations.

7.8 Recording the conversations with ongoing consent

Each conversation was recorded on two devices, to ensure that should technology fail a backup copy was available. Prior to pressing record, all participants were asked if they would be happy for the conversations to be recorded, and after their verbal confirmation I then informed them that I was beginning to record the conversation. At the end of each conversation, I also informed them that I was going to stop recording.

All in-person conversations were recorded using an audio recorder that was only being used for this research inquiry, recording to a dedicated memory card, along with using the audio recording App on a personal password-protected iPhone device. Video-conference based conversations were recorded using a University of Birmingham Zoom account (both video and audio) and were also recorded using the audio recording App on a personal password-protected iPhone device. Transcripts were produced from the audio recordings. All personal information (such as names and locations) was removed during the transcription process. All the transcripts were provided to parents for checking and feedback. No comments, amends or deletions were requested.

7.9 Data storage

The transcripts, copies of email correspondence and photographs of the initial objects/documents brought to the initial conversation have been deleted from personal devices and transferred to the University of Birmingham OneDrive. They have also been stored on the University of Birmingham’s secure BEAR system, according to the approved

Data Management Plan[46] for this inquiry. All personal identifying information has been redacted.

7.10 Starting the conversations

The initial research conversations/meetings all took place between July to September 2021. As discussed above, five of these initial meetings were face-to-face and two (for the two mothers who lived in the North of England) were held on Zoom. For those meeting face-to-face, I asked them to suggest when and where we could meet. I visited some homes and met others in coffee shops local to their homes. I am grateful to those who invited me into their homes, whether in person or on Zoom, as I recognise that they welcomed me into their personal space. Likewise, I am grateful to those who travelled to meet me too. I recognise this required a greater time commitment for them.

Before the initial meeting, I asked each mother to:

- Reflect on their experiences as a parent of a child with Down syndrome, specifically in relation to inclusion and what decisions they have made about their education – what has influenced them, what did they think about, any events, experiences, conversations, or interactions that stand out to them, people who have influenced

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[46] See Appendix Six

what they think is possible, as well as anything else in relation to this general topic (ie. parenting, inclusion, education) that they wanted to discuss.

- Bring along a conversation starter – I suggested this could be writing down their experiences, drawing a picture, writing a poem, choosing an object that signifies something important, a piece of documentation/report, something that they had written, eg. for the EHCP process, online or in a diary, or a photograph/video.

The seven conversation starters brought to these initial meetings were:

- 2 x home-school diary/communication books;
- 1 video of a school nativity play;
- 1 whisk;
- 1 blog post;
- 1 definition of inclusion downloaded from the Internet;
- 1 document that had been produced with other parents in preparation for a forthcoming SENDIST tribunal hearing.

Image 7: George’s whisk

Conversation starters were introduced as a way to begin the conversations with a topic, focus or idea that originated with the mothers. This was to ensure the conversations were inclusive of their agendas or interest in taking part in this inquiry. I did not want to limit parents in how they started their conversations with me, hence providing a wide range of items that they might consider bringing including things they had created themselves. The conversation starters were never intended to be analysed in and of themselves, ie. for meaning or what they signify, rather the purpose was to see what they might produce within the conversation, where the conversation might flow.

7.11 Ending the conversations

I knew from the outset of this inquiry that there was a possibility I might need to artificially draw the conversations to a close. This was going to be necessary as the parents engaging in the research had the right to withdraw from the study up to three months after the final meeting. If there was no formally stated final conversation/meeting, then there would be no date from which they would be able to withdraw from the inquiry. Therefore, in May 2022 I emailed all the participants with a view to arranging a final conversation, within which I provided them the opportunity to reflect and provide feedback – good and bad - on their engagement in the inquiry. Two of these final conversations were by telephone, one was face-to-face, and two were via a Zoom conversation. I had arranged to meet the other two parents face-to-face, but then needed to rearrange because I caught COVID-19 in June 2022[47]. One of these was rearranged but then had to be cancelled due to illness in their household and a second date was cancelled due a diary clash. We then went into the school holidays, and despite emailing both remaining parents, I was unable to arrange a date with them for this final conversation.

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[47] I should have realised that going to Glastonbury was a bad idea!

In September 2022 I wrote to both mothers stating that I needed to draw the formal research conversation to an end, inviting them again to arrange a final meeting but that if they did not want to or were unable to, the research data collection would finish on 30 September 2022. One of the remaining two parents asked me if she could respond in writing, as she found this easier than meeting, and she sent me her feedback by email, but I did not hear from the second parent before the end of the month.

I discuss the feedback received from the mothers who took part in the inquiry in Chapter Twelve.

8. APPROACHING ANALYSIS

8.1 Introduction

As I have previously discussed, I engaged in conversations with seven mothers of children who have Down syndrome over a 12-month period. These conversations were recorded and transcribed but were never intended as ‘data’ to be ‘analysed.’ Rather than assuming ‘voice can speak the truth of consciousness and experience’ or that it is ‘a mirror of the soul, the essence of the self’ (Mazzei & Jackson, 2009:2), this inquiry starts with a position that when we recount our experiences, these accounts are always ‘bring[ing] forth the very life which they speak’, producing and doing something new (Jackson & Mazzei, 2023:2).

Therefore, within this thesis you will not find a discrete analysis of the ‘data’ from the conversations, which would imply a ‘static capture of text’ (Jackson & Mazzei, 2023:viii). Nor do I attempt to ‘give voice’ to the parents who engaged in the research, which suggests voice exists as something that can be retrieved or liberated (Mazzei & Jackson, 2009). Instead, I have attempted to engage in a process of ‘plugging in’ (Jackson & Mazzei, 2013:262) the conversations when thinking with theory, whilst simultaneously also plugging in theory whilst engaging in the conversations with parents. This extends the approach suggested by Jackson & Mazzei (2012:5), who ‘work[ed] the same data chunks repeatedly’ by ‘plugging in’ different poststructuralist theories to create something new. Whilst I similarly wanted to work ‘with unstable subjects and concepts-on-the-move… in a process to diffract, rather than foreclose thought’ (Jackson & Mazzei, 2012:5), in this inquiry my aim was to think with theory in conversation with the research participants in a continual intra-active process. This approach aims to unsettle the stable subject positions of both researcher and researched, putting to work both theory and the knowledges of parents of disabled children, allowing new meanings and connections to be made and unmade in a 'doing' (Jackson & Mazzei, 2023:2).

In Chapters Nine, Ten and Eleven, I present emerging threads that discuss the actions mothers of disabled children undertake, the materiality and affect of documentation, and belonging, that have been informed by my own personal experiences as a mother of a disabled child *and* the conversations with parents that I have engaged with during this inquiry *and* the education and philosophical texts that I have engaged with before and throughout this inquiry, '*AND... AND... AND...'* (Deleuze & Parnet, 1977:10, emphasis added). As Jackson & Mazzei (2023:1) describe this thesis is therefore 'both a collective and a middle', a becoming that is '"unattributable to individuals," a collective immersion of lines "without a subject, without beginning or end"'. This onto-epistemological approach recognises that we are always plural and relational (Deleuze & Guattari, 1987; Manning & Massumi, 2014). The thesis does not present data that has been captured and analysed, rather this is a thesis that is continually becoming in-between a felting of philosophical inquiry and conversation with mothers of disabled children.

8.2 Analysis in conversation

As discussed above, an important aspect of this inquiry was the shift away from thinking about voice as 'the coherent, stable, disembodied and valorized emblem of individual selfhood and authenticity' (Chadwick, 2020:1). Accordingly, maternal voice is not something that can be discovered or revealed by my analysis or representations. Instead as Chadwick (2020:1) describes, this inquiry recognises voice as an ‘emergent and unpredictable process involving fleshy bodies, more-than-human elements and the vitalized intertwining of discursive, ideological and sociomaterial relations’. It has been intentionally designed to be an inquiry that is ‘becoming with researchers, participants, and the whole research process’ (Østern et al., 2023:285). My aim therefore has not been one of emancipation, rather to listen respectfully to mothers’ stories, to engage in conversation and to be affected by their opinions and experiences.

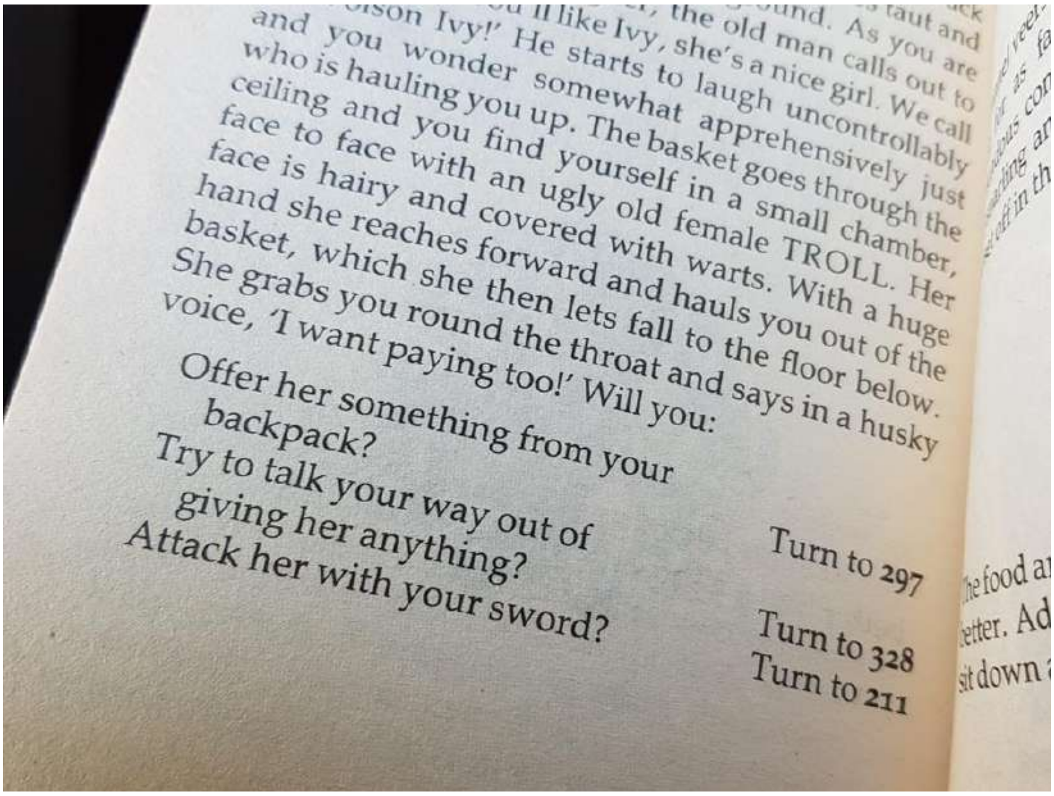
Together – in conversation - we explored what it means to be included or excluded from education. When employing a mode of inquiry that is ‘moving, diffracting and multivocal’, it is also important to employ analytic approaches that are sensory and affective (Chadwick, 2020:5). A posthuman analysis requires a researcher to explore, trace and attend to ‘interruptive voices’, where the analytically most interesting voices are those that are ‘wild and excessive’ that defy easy categorisation. This required an attunement to listening and ‘becoming-with’ as the conversations shifted, morphed, and produce new ways of thinking, being and relating to one another (Chadwick, 2020:6-7).

I returned to the typed transcripts after our conversations had ended, dwelling with them, allowing myself to be affected by the stories that had been told, thinking with the ideas that were emerging as I read and re-turned to the conversations that had taken place whilst also reading previous research and philosophical theories. Although the conversations were recorded and transcribed, this was not with a view to undertake ‘conversation analysis’, to explicate and communicate explicit meaning (Gillespie & Cornish, 2009). Rather, as Harrison et al. (2020:408) describe, the conversations provided both me, as researcher, and the mothers engaged in the inquiry with a 'space to think, to verbalise our ideas, to hear others, to raise questions and reframe our thinking'.

As I re-turned to the transcripts, I paid attention to the affective nature of re-turning to the conversations, noticing what was '"happening" in the moment of reviewing' (Salter, 2021:390), being drawn once again to the aspects that 'glow' (MacLure, 2013:661). This approach to analysis does not emerge from a 'distant, disembodied position', rather it recognises how the conversations that took place have 'affective capacities' and 'agential forces', and the 'research material, the process and [myself as] the researcher perform on one another, constantly in-becoming' (Østern et al., 2023:285). As such, the conversations both informed and inspired the three threads of this thesis that follow in later chapters; the conversations enabled new theoretical explorations to come to life, in a process Salter (2021:391-2) describes as 'future forming' as they created 'new possibilities for transformation'.

8.3 Choose your own adventure

When I was a child, like millions of preteen children of the early 1980s, one of my favourite types of books to read was the 'Choose Your Own Adventure'. In these popular books, the reader was addressed in the second person and was asked to make a choice at the bottom of the page as to what action to take next, from which you would be directed to a different page in the book to continue the adventure. Depending on what choices you took along the way, you would find yourself in one of multiple possible endings. Part of the fun was revisiting the book and making different choices, to see where that might have taken you instead. Readers flip back and forth, making different choices to find the ‘golden ending’ that they were hoping for (Karunatilaka, 2023:unpaginated). The interactive choices gave readers ‘a sense of autonomy, agency and emancipation’ (Cook, 2020:425), though frustratingly on occasion, choices made could throw the reader into a never-ending and inescapable loop ‘where they repeatedly reach the same page (often with a reference to the situation being familiar)’, leaving the reader with no option but to start again (ChooseCo, 2023).



taut and
und. As you are
, the old man calls out to
ll like Ivy, she’s a nice girl. We call
ison Ivy!’ He starts to laugh uncontrollably
and you wonder somewhat apprehensively just
who is hauling you up. The basket goes through the
ceiling and you find yourself in a small chamber,
face to face with an ugly old female TROLL. Her
face is hairy and covered with warts. With a huge
hand she reaches forward and hauls you out of the
basket, which she then lets fall to the floor below.
She grabs you round the throat and says in a husky
voice, ‘I want paying too!’ Will you:

Offer her something from your backpack? Turn to 297
Try to talk your way out of giving her anything? Turn to 328
Attack her with your sword? Turn to 211

Image 8: A page from a Choose Your Own Adventure book

Part way through the conversations with the parents engaged in this inquiry, Sita suggested that she would be interested to know what the other mothers taking part in the inquiry were discussing with me. I had not anticipated this suggestion and sat with it for a while, thinking about how I might be able to do this, without either breaching confidences or having a significant influence on how future conversations might proceed. I was concerned that by hearing what others were saying, it might prevent someone from discussing something important to them or feeling concerned about offering an alternative opinion. I was also unsure about how I might even start to pull the conversations together into something that could be shared, given that the conversations were designed to move thought forward and remain open-ended.

First, it was necessary to do was to ask the other parents if they were also interested in hearing what the other parents had been discussing and to seek their permission for me to share anonymised information about our individual conversation with everyone else. There was unanimous written agreement to proceed. I was still left, however, with needing to find an approach that would remain open-ended, that resisted shutting down aspects of the conversation. I started to think with Strom & Mills's (2021) article, where they discussed their approach to undertaking a diffractive book 're-view', in which they used hyperlinks throughout the article to act 'as lines of flight, creating momentary ruptures that exceed/subvert the representational logic and linear sequencing of [their] paper' (Strom & Mills, 2021:189). I had enjoyed engaging with this article and clicking through to the links that added additional detail, taking me to places outside of the main structure of the article.

It reminded me a little of the Choose Your Own Adventures of my childhood. A seed of an idea was planted.

Wondering if I could maybe introduce hyperlinks throughout the document, to allow for a rhizomatic reading, I returned to the transcripts, paying attention to the topics that either set off new thinking for me, or that had been repeated or returned to in the conversations, seeking both lines of flight and the refrain (Deleuze & Guattari, 1987). This was a very manual and hands on process, I sat with pen and notebook, reading and re-reading the transcripts, jotting notes, thoughts, drawing lines across pages, making connections between the conversations but also returning to the moments that had been particularly affective, that had stuck with me, that I had carried with me from conversation to conversation. For each parent I used a different colour pen, and soon my notebook was a rainbow of jotted notes and multi-coloured lines making connections. These were the connections I used as hyperlinks in writing the emerging document to be shared, to link different sections together, encouraging the future reader to choose whatever pathway they wanted to through the document.

At the beginning of the document, I wrote a letter for the parents to explain my approach, explaining that the document had been designed to share things we had discussed, but without wanting to fix the conversations. I encouraged them all to read the initial section and then to choose a heading that stood out to them as particularly interesting, and from that see where the adventure might take them. We would then use their reading as the starting point for the conversation the next time we met.

This approach was not completely true to the original Choose Your Own Adventure books. I recognise that the original books gave an illusion of free choice, yet provided limited decisions to be taken that would lead to a fixed number of endings created by 'choice architects' (Cook, 2020:425). Whilst I created the hyperlinks which may have shaped some possible pathways through the document, there were no end points that would be reached, but more importantly the parents were given the freedom to engage in the document in whatever way they chose, indeed they did not need to read it at all if they did not want to. As Hendren (2020) describes, even when humans have designed a space imagining the lines that will be followed, individuals often zig-zag in ways that make sense to them, creating desire lines that may never have been anticipated. In their reflections, one parent described how she constantly returned to it as different aspects came to mind, another described reading it from beginning to end without using the hyperlinks, because she did not want to miss anything important.

There were moments when I felt concerned about the introduction of this document introducing a range of themes. It felt like a traditional thematic analysis of 'data' generated through the conversations that had taken place. This was something that I had originally wanted to avoid, the idea that the conversations could be represented and fixed into themes. I was aware of St. Pierre's reminder that:

> post qualitative inquiry is not a rejection of qualitative inquiry or any other preexisting social science research methodology. It is something different altogether and cannot be recognized and understood in the same grid of intelligibility as those methodologies (St. Pierre, 2021:5).

Events such as this highlight how tensions can exist when – as part of an inquiry using poststructuralist and posthuman theories – it appears to make sense to use a more traditional approach, leading to what Montforte & Smith (2021:650) describe as the potential 'problem of incommensurability and onto-epistemological incoherence'. However, these research approaches do not need to be seen in oppositional ways, an attitude that can lead to a sense of hierarchy and the discrediting of other work to justify one's own approach (Montforte & Smith, 2021). There is no one 'right' way of undertaking inquiry and it can be a constructive move to blur some of the boundaries between different paradigmatic views (Montforte & Smith, 2021). Smith (2019:2) discusses the importance of 'disciplinary crosspollination' or what he calls 'methodological syncretism' where you combine elements which might be seen as ontologically incompatible 'in the hope of creating fractures and fissures through which new ways of doing and being research/researcher might arise'. He further argues that it is important for researchers to recognise that 'there are legitimate onto-epistemic issues with blending traditional humanist methods with postqualitative sensibilities' so there is no need for dogmatic abandonment of traditional qualitative approaches (Smith, 2019:9). I was reminded of this again at the ECQI conference in 2023, as Kuntz (2023) suggested in his presentation about thematic analysis that whilst filtering and reducing 'data' into themes can result in the same, ie. what we already know and understand, it is possible that creating, philosophising and 'writing with themes' can be a form of diffractive analysis that embraces a 'peripheral resonance, one that feels different', enabling an exploration of something new as part of an analytic assemblage. Therefore, I am comfortable that the document produced could be considered a form of thematic analysis that might feel out of place in this inquiry. What matters is what piece of writing that was shared part way through the research inquiry produced, where it led to, rather than what it 'is' or what it 'says'.

The document produced played an important part in this inquiry in numerous ways. Firstly, it was produced from the initial conversations, but also it only came into being because of one of the conversations. Its production and how the parents engaged with the document in a variety of different ways fed into further conversations that took different directions. It allowed me to bring each of the parties of the individual conversations into relation with each other. Interestingly, this brought the parents some comfort in knowing that they were not alone in the challenges they faced. It gave them strength too. Faith described how:

> *There have been many occasions where I have felt helpless, shedding tears every day became the norm as I didn't see anything changing. However, through this investigation, I started to regain my strength and realized that I was not the only one going through this process, I learned that there was a ton of people who shared the same experience as me: This inspired me to continue fighting for my son's equal rights to a decent education.*

The production of the rhizomatic document brought the parents further into the process of ongoing analysis, rather than the analysis all taking place after the conversations had ended. The use of themes did not shut down the conversations, rather the approach taken recognised the mothers' engagement in the research process as important and ongoing.

8.4 Incorporating creative research methods

During the process of this research inquiry, I started to explore different creative research methods, to support both analysis and dissemination of the findings to move away from linguistic representation. Instead of providing representations of the mothers and what they said, I wanted to find a way to communicate continuing affects, movements, emerging but tentative meanings and materiality within the inquiry (Honan, 2014). Instead of providing an analysis of an interview, where I as interviewer 'upholds a monopoly of interpretation' (Kvale, cited in Honan, 2014:11) and flatten words on a page, I wanted to find a way to communicate the 'in-between', to 'unfix the speaking subject from the fixing of words on the page' (Honan, 2014:13). Within the philosophies that underpin this inquiry, language is just 'one element in a manifold of forces and intensities that are moving, connecting, and diverging, and it is necessary to embrace that which is 'resonating in the body as well as the brain', to provide space for the 'not-yet-articulated' (MacLure, 2013:660-1). To embrace becoming. To present and re-present knowledge differently.

My engagement with arts-based methods allowed a further embodied experience as I brought the conversations and theory together with materiality, incorporating material matterings into the meaning-making process (Harding, 2023). Kuby et al. (2022:287) describe how bringing together people, materials and ideas together can provide a 'theoretical playspace to (re)think identity and subjectivity.' I wanted to be able to experiment and spend time in this space, to see what might emerge. I knew that it was necessary to find a way to resist any pull of presenting a 'true' representation of the conversations that had taken place, meaning that I needed to find an approach for both analysis and dissemination that would have the potential to foreground an unknowing, an undoing and an unfinished conversation still in progress. A becoming that remains full of possibilities.

Embracing playfulness in research inquiry can 'creat[e] cracks in the existing knowledge' and has the potential for the unfolding of new forms of knowing, learning and relation (Pyrry, 2022:76). Creative outputs, such as those I use in this inquiry, can embrace multiplicity and texture and can be unsettling, rebellious, collaborative and dynamic (Johnson, 2022). My aim therefore was to incorporate arts-based analysis in a way that is entangled with the text of this thesis, allowing greater possibilities to emerge as visual methods and the written word are encountered alongside and between each other.

8.4.1 Discovering collage

I feel significantly more comfortable with using the written word than I do using creative approaches to research, so I had to push myself out of my comfort zone to incorporate an arts-based approach within this inquiry. This was a productive discomfort however, and a risk I was willing to take, in the anticipation that by doing something outside of my usual approaches to thinking and writing, there would be further potential for generating new insights and ways of approaching inclusion. During the inquiry, at a time when I had started thinking about emotions and affect in research, I saw an opportunity to take part in a project using zines to think about the role of emotions in research called '*Researchers Don't Cry?!*' (Ptolomey, 2021). I felt drawn to the project, believing that it would be generative for my own research approach. In trepidation, I joined the zine-making workshop, and surprisingly I really enjoyed the session. I was particularly interested in how different layers, textures, and space on the page could be used in a non-linear way to create multiple connections.

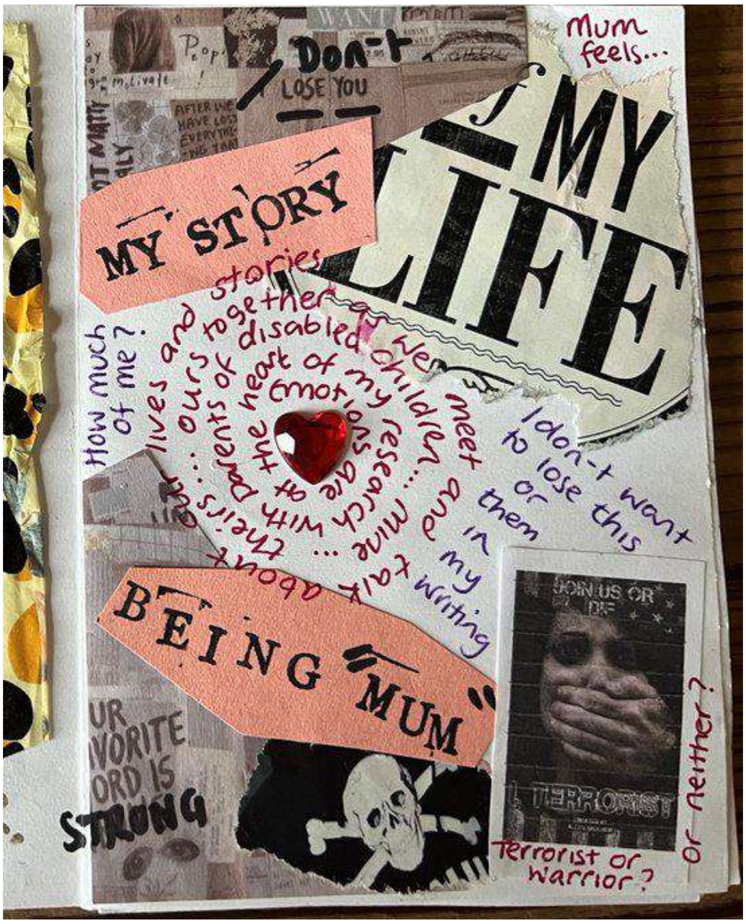


Image 9: A page from the zine made during the *Researchers Don't Cry?!* workshop in 2021.

Shortly after, I also had the opportunity to attend a *'Scrapbooking the Wasteland'* workshop (de Bruin-Molé, 2022), where attendees were invited to engage in collaborative scrapbooking/collage. Having enjoyed the zine making workshop, I decided to attend to find out more about how this approach might be incorporated in my own research practice.

Image 10: Collaborative scrapbook page from the '*Scrapbooking the Wasteland'* workshop in 2022.

I found this art-based method to be both generative and therapeutic, and that it allowed the playfulness and the space to think differently about the concepts I was engaging with theoretically. This approach could provide a way to bring conversations and theory together to create something new, whilst also allowing for a non-linear presentation of aspects of the inquiry to be shared, for instance affects of conversation. Collage allows the viewer to choose their own path through the imagery produced, making their own connections, and generating their own understandings.

8.4.2 Using collage and scrapbooking in this inquiry

> She had been working on it for fifteen years, carrying about with her a shapeless bag of dingy, threadbare brocade containing odds and ends of colored fabric in all possible shapes. She could never bring herself to trim them to any pattern; so she shifted and fitted and mused and fitted and shifted them like pieces of a patient puzzle-picture, trying to fit them to a pattern or create a pattern out of them without using her scissors, smoothing her colored scraps with flaccid, putty-colored fingers (Deleuze & Guattari, 1987:476).

Collaging uses a range of materials that were intended for something else, that are cut, torn, shredded or drawn on and stuck onto the page, with various textures, pictures and materials layered over each other. Some aspects are incomplete, others are partially covered, and some are transformed through the addition of other materials. As Hogarth et al. (2022:6) explain, collaging 'comes from the French term "papiers colles" or "decoupage" and involves cutting and then pasting together/layering'. Collage reaches beyond traditional academic writing, recognising the value of bringing matter and discourse together, in a way that foregrounds 'doings, practices, and actions' (Bozalek et al., 2021:845). Morgan describes how collage can resemble 'the interchanges of conversation: associative, additive, interruptive' (Morgan, 2000:141). Given that this inquiry utilises conversation as research this seems particularly pertinent.

Collage resists the idea that there can be one interpretation, instead embracing multiplicity and difference. It enables a different thinking-with data and theory, allowing new ideas to take shape as the materials are played with. These materials, which might have previously been disregarded as waste or scrap materials, now 'bounce and shape still more ideas' (Kuby et al., 2022:289). This approach further resists the idea of analysis ever being either perfect or finished, instead it is enacted in an ongoing performative process of doing and undoing. At times I was much clumsier than I wished to be, cutting slightly too much off or the paper ripped in a direction I did not want or had not anticipated, but I continued to work with the materials in their becoming, recognising that I was not in full control of the process. As Safron (2019:47) describes, engaging with collage can be ‘somewhat of an unpredictable mess’ – but that is what I have found to be appealing and generative.

Working with collage allows the transformation of material objects, which are taken out of context and given new life, whilst ‘always retaining an air of alienation that resonates with the complexity of human relationships’ (Vandecasteele et al., 2021:486). As Vandecasteele et al. (2021:485) describe, such arts-based practice allows method and theory to be blurred and challenged, producing ‘a different kind of knowledge than the measurable knowledge with which we are traditionally familiar’. It troubles prevailing ideas of ‘what knowledge might look like’ (Pyrry, 2022:69). Pyrry (2022:66) argues it is necessary for us to attend to our ‘shared affective landscapes’ when undertaking research and to recognise that we ‘learn with our “thinking-feeling” (Massumi, 2015) bodies’. Knowledge can be generated through affective encounters that generate new ways of seeing the world, but sometimes these encounters cannot easily be articulated using words.

As I explain in my discussion of the SENDIST tribunal (see Chapter Five) ‘bodily knowledge’ should be recognised as a significant part of our engagement in research (Pyrry, 2022:75). Using collage enables such an engagement with embodied and affective processes of undertaking research, capturing that which is bodily and fleeting (Vandecasteele et al., 2021).

Importantly, creative forms can help express the ‘moods, emotions and sensations’ that can arise during research (Poli & Andrieu, 2022:118), producing an affective and emergent liminal space that ‘makes visible what could only be imagined’ (Flint, 2018:16), or felt but not easily articulated[48]. Engaging in a playful collage creation enables an aesthetic reflexivity that allows feelings, assumptions and values that might otherwise be hidden or unspoken to surface and be explored (Woods et al., 2023:601). This is a ‘visual and embodied thinking rather than linear, linguistic thinking’, which is useful for ‘times where words are inadequate’ (Woods et al., 2023:606). This affective process therefore allowed pre-reflective knowledge to emerge through my felt bodily senses as I interacted with a range of images and materials (Woods et al., 2023).

Collage can be seen as something similar to creating a ‘montage’. Bozalek et al. (2021:846) describe how the process of montage ‘can be compared with picking up crystal fragments and examining them through different light rays’ allowing ‘insights to “flash up” in new constellations. The fragments within the montage or collage are neither linear nor necessarily directly related, and this allows for ‘shifting diffraction patterns’ which allow for insights to be generated by those viewing the finished piece (Bozalek et al., 2021:846). Each fragment is in a process of becoming-with each other in the collage, as the viewer responds to each individual fragment in its relation to the whole.

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[48] During my ongoing discussions to secure provision for my daughter post-tribunal, I sent one of my collages to the SEND team. It was out of pure frustration at not being able to communicate the impact of their intractability on us as a family. Unsurprisingly, they did not respond.

The collages produced in this thesis embrace multiplicity, rejecting notions of linear or hierarchical knowledge, instead producing '*a map and not a tracing'* (Deleuze & Guattari, 1987:12, original emphasis). As Deleuze & Guattari describe, a 'map is open and connectable in all of its dimensions; it is detachable, reversible, susceptible to constant modification' (Deleuze & Guattari, 1987:12). The collage is never finished, elements can be removed, covered, moved or added as required. Importantly there is no one way in, rather there are multiple entry-points, with no beginning or end, 'just middles' (Alvermann, 2000:116). The words, phrases, memories and affects from the conversations with parents become entangled with the images and words cut out from magazines, which became entangled with the journals and books I was also thinking-with. As a result, elements that were previously silent or hidden might come to the fore, grabbing my attention as I assembled and re-assembled the various elements in the collage. Through this process, the collages were formed and reformed, in a type of 'patchwork, which fits together pieces of varying size, shape, and color', playing with the texture and imagery of the materials used, coming into being 'piece-by-piece' with 'infinite successive additions', in a space that has no fixed centre and is 'not all constituted in the same way' (Deleuze & Guattari, 1987:476).

Whilst the collage might stay the same, it has the potential to become something different every time it is re-viewed. As Vandecasteele et al. (2021:488) describe, collage as patchwork should 'not be seen as static and final: it is a temporary explication of an on-going process, an open-ended experiment'. Collage – similarly to how this inquiry has utilised conversation - is not designed to capture meanings but to 'bring them to life (again)' by engaging with complexity and strangeness (Vandecasteele et al., 2021:486).

8.4.3 Poetic transcription to ‘stay with the magic’

> Poetry invites us to listen. Poetry is a site for dwelling, for holding up, for stopping … Poetry is about rhythm … Poetry creates textual spaces that invite and create ways of knowing and becoming in the world (Leggo, cited in Faulkner, 2020:11-12).

A serendipitous find when browsing an independent bookshop on holiday, *Creative Histories of Witchcraft* (Corbett et al., 2022)[49] provided a further powerful call to me to embrace imaginative research techniques when writing research. Seeking ways to tell stories that are ‘multivocal and undecided’, the authors of this book work with theatrical and poetic techniques drawing on ‘found materials’ in ‘a process of discovery’ engaging with fragments and bringing them together anew (Corbett et al., 2022:11-12). They describe how writing ‘becomes a form of noticing’ and offers a way of bringing the reader ‘close’ to the voices being re-presented in creative form (Corbett et al., 2022:12). Every word used matters, as does the utilization of space on the page (Corbett et al., 2022). Accordingly, the authors suggest a need for researchers to ‘stay with the magic’ to write, think and feel differently (Corbett et al., 2022). On reading this book, I recalled the intensities and power of the words used by the mothers in our conversations and felt an urgent need to find a way to incorporate these alongside the developing threads. I wanted readers of this thesis to be affected by their words in the way that I had been.

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[49] I had been reading about witchcraft and the demonisation of some women in society, as a side interest to this doctoral inquiry.

I started reading more about poetic transcription, which is ‘the creation of poem like compositions from the words of interviewees’ (Glesne, 1997:202). There is no predetermined way to undertake ‘the transformation of interview transcripts into poetry’ (Glesne, 1997:205). Richardson (1992:126) describes how she fashioned text from a typed transcription, using poetic devices such as ‘repetition, off-rhyme, meter, and pauses’ to produce a poem that lends itself ‘to multiple and open readings’. Glesne (1997:206), inspired by Richardson, followed a process where they read and re-read the transcript before choosing words from the transcription that would illuminate ‘the essence conveyed, the hues, the textures’. Offering an example that is closer to the focus of this inquiry, Faulkner (2020:7) articulates how she has written ‘mother-poems to lay naked the taken-for-granted assumptions and social structures around mothering’ as feminist, liberatory praxis. My aim is to do similar in relation to mothers of disabled children, to push back against some of the stereotypes, binaries and assumptions that underpin current discourses and research agendas. Faulkner further suggests that poetry can be combined with collage as a form of critique related to the normative expectations relating to motherhood. The poems ‘found’ in this inquiry will therefore sit alongside and between collages that have been produced to ‘evoke embodied responses in listeners and readers’ (Faulkner, 2020:15).

As Fairchild (2023:144) describes, instead of writing fixing events in the past, bringing poetry alongside theory can ‘harness the becomingness of the event’. As I immerse myself in theory and in the process of ‘writing-with’ the transcripts that were produced from the conversations, it becomes possible to ‘move beyond linear modes of thinking and writing’, to ‘infuse with creative potential’ and to activate the ‘potential of the not-yet-known’ (Fairchild, 2023:136-7). Poetical thinking therefore ‘represents a shift from an epistemological and representational way of knowing to an ontological, non-representative way of thinking’ (Sanders & Lamm, 2022:1). Poetry highlights everyday experiences in a way that is evocative and affective, as it touches the reader emotionally (Richardson, 1992). As such, it offers readers an invitation ‘to experience new feelings and understandings’ as they engage with the complexities of the lived experience of the Other (Sanders & Lamm, 2022:3). As Lees & Overing (2019:45) describe, poetry ‘is public conversation with a communal audience’. Again, returning the importance of conversation within this inquiry. The use of poetry allows me to extend the conversations that took place to a wider audience through word-play, without any suggestion it is a ‘true’ representation of the events that took place.

Unlike traditional poetry, where any topic or words might be used, creating poetry from transcripts relies on the words spoken by research participants (Keith & Endsley, 2020). The researcher acts as a filter through which participants’ words become ‘charged, intensified, concentrated’ (Drury, cited in Glesne, 1997:213). Importantly, poetic transcription entails a ‘burden of care’ (Yi & Mackey, 2023:6) when representing participants’ words, as the words are extracted, positioned, repositioned, and re-presented in a new form. I felt a keen sense of responsibility to ensure that participants’ words can be read and heard, as I chose which words to use from our multiple conversations when crafting the poetic transcriptions. Every time I re-turned to the transcripts I would see and feel something new emerging – new invitations, new provocations, new disturbances, new meaning-making – as I engaged with multiplicities of experiences and thought (Carlson et al., 2023; Fairchild, 2023). My hope is that this deeply affective engagement infuses the poems presented throughout this thesis, as I experiment, write, and attempt to stay with the magic throughout the following threads.

9. THREAD – AFFORDANCES

9.1 Introduction: Becoming 'mum'

Image 11: Badge photo shared by Emily during a conversation

> *It was a dig at our SENCO… you know, it bugged me so much… because she just always calls you mum, mum, dad, mum, mum, mum, mum, mum and I just thought do you know what, I've had enough* (Emily).

In the first part of this chapter, I discuss how mothers of disabled children are described in both practice and research. Through a detailed and critical engagement with academic literature, I examine how the identities and subject positions that mothers of disabled children are seen to occupy may impact both on how they see themselves and importantly how they are related to by others. In the second part of this chapter, I bring together Dokumaci's concept of activist affordances (2020; 2023) with the conversations that took place as part of this inquiry, to offer an alternative way of thinking about the role of mothers of disabled children when attempting to secure their child's inclusion in education.

This chapter specifically responds to Goodley's call to move away from thinking about 'bounded' subject positions for mothers of disabled children, previously discussed. Goodley claims that such positions 'can be dangerous in the ideological battlefield of disability politics and the sociology of disability' as they suggest 'some parents are seen as better than others' (Goodley, 2007:146). Drawing instead on activist affordances allows a recognition of maternal engagement with education as a 'process of becoming—or not yet being' (Goodley, 2007:146), offering a way to move away from problematic hierarchical thinking and the simplistic categorisations of mothers.

9.2 Part 1 – Being 'mum'- the categorisation of mothers of disabled children

9.2.1 Mothers as 'champions' or 'saboteurs'

In 2021, I attended an online event run by Whole School SEND[50] about parent engagement, during which a Specialist School Headteacher presented a framework that she had developed to support greater positive engagement with parents. Hanna (2021) suggested that it was necessary to consider what type of parent each parent in an education setting might be, ranging from 'Champion' to 'Terrorist', from which teachers could determine the best way to engage with them.

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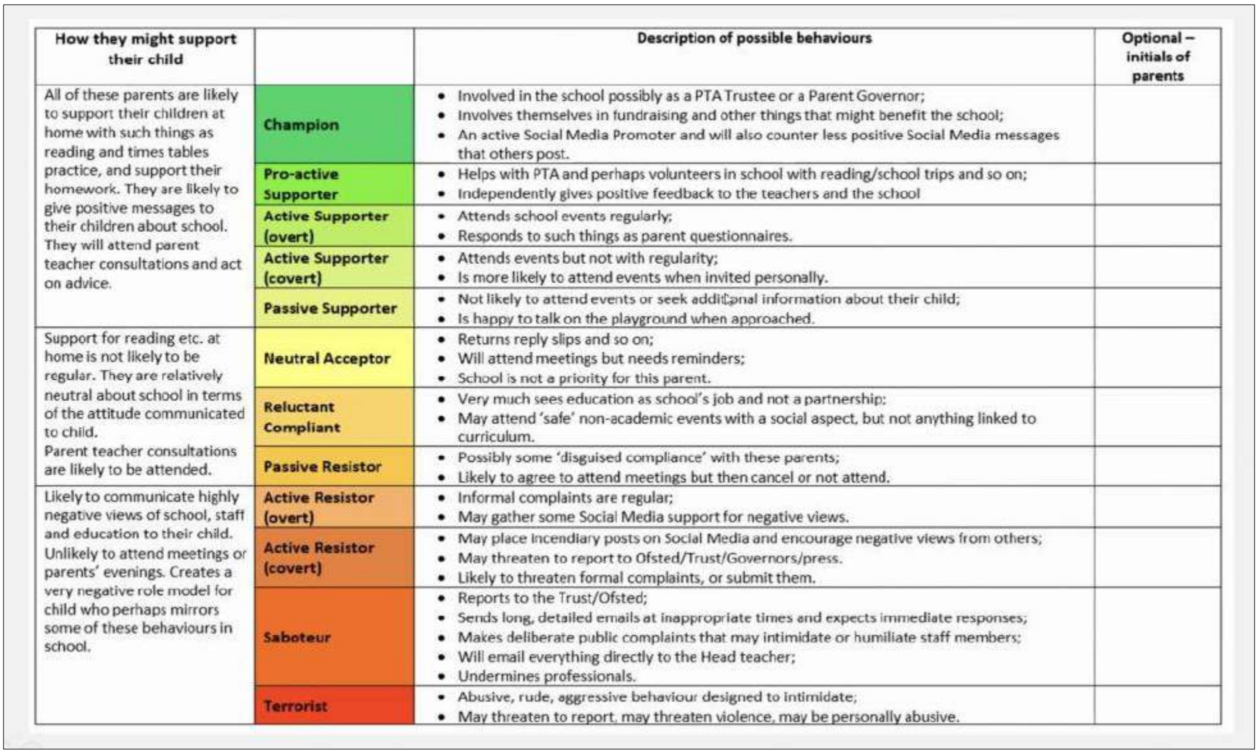
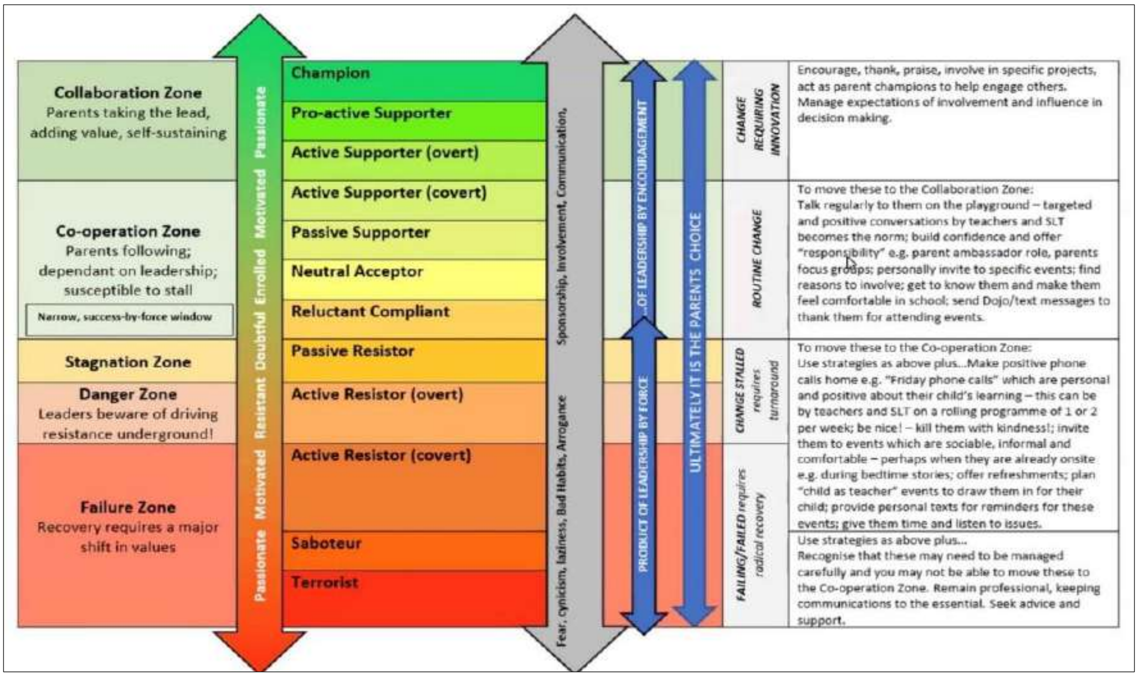
[50] It is important to note that Whole School SEND have subsequently apologised that this was presented in one of their Webinars and have confirmed that this framework is not a Whole School SEND approach to working with parents, whose voice should be valued. They also invited me to run a session with their regional leads, to discuss language in relation to parents of disabled children.

Two screenshots from the presentation are presented below:



How they might support their child		Description of possible behaviours	Optional – initials of parents
All of these parents are likely to support their children at home with such things as reading and times tables practice, and support their homework. They are likely to give positive messages to their children about school. They will attend parent teacher consultations and act on advice.	**Champion**	• Involved in the school possibly as a PTA Trustee or a Parent Governor; • Involves themselves in fundraising and other things that might benefit the school; • An active Social Media Promoter and will also counter less positive Social Media messages that others post.	
	Pro-active Supporter	• Helps with PTA and perhaps volunteers in school with reading/school trips and so on; • Independently gives positive feedback to the teachers and the school	
	Active Supporter (overt)	• Attends school events regularly; • Responds to such things as parent questionnaires.	
	Active Supporter (covert)	• Attends events but not with regularity; • Is more likely to attend events when invited personally.	
	Passive Supporter	• Not likely to attend events or seek additional information about their child; • Is happy to talk on the playground when approached.	
Support for reading etc. at home is not likely to be regular. They are relatively neutral about school in terms of the attitude communicated to child. Parent teacher consultations are likely to be attended.	**Neutral Acceptor**	• Returns reply slips and so on; • Will attend meetings but needs reminders; • School is not a priority for this parent.	
	Reluctant Compliant	• Very much sees education as school's job and not a partnership; • May attend 'safe' non-academic events with a social aspect, but not anything linked to curriculum.	
	Passive Resistor	• Possibly some 'disguised compliance' with these parents; • Likely to agree to attend meetings but then cancel or not attend.	
Likely to communicate highly negative views of school, staff and education to their child. Unlikely to attend meetings or parents' evenings. Creates a very negative role model for child who perhaps mirrors some of these behaviours in school.	**Active Resistor (overt)**	• Informal complaints are regular; • May gather some Social Media support for negative views.	
	Active Resistor (covert)	• May place incendiary posts on Social Media and encourage negative views from others; • May threaten to report to Ofsted/Trust/Governors/press. • Likely to threaten formal complaints, or submit them.	
	Saboteur	• Reports to the Trust/Ofsted; • Sends long, detailed emails at inappropriate times and expects immediate responses; • Makes deliberate public complaints that may intimidate or humiliate staff members; • Will email everything directly to the Head teacher; • Undermines professionals.	
	Terrorist	• Abusive, rude, aggressive behaviour designed to intimidate; • May threaten to report, may threaten violence, may be personally abusive.	

Image 12: Hanna's presentation slide re behaviours (Hanna, 2021)



Collaboration Zone
Parents taking the lead, adding value, self-sustaining

Co-operation Zone
Parents following; dependant on leadership; susceptible to stall

Narrow, success-by-force window

Stagnation Zone

Danger Zone
Leaders beware of driving resistance underground!

Failure Zone
Recovery requires a major shift in values

Champion
Pro-active Supporter
Active Supporter (overt)
Active Supporter (covert)
Passive Supporter
Neutral Acceptor
Reluctant Compliant
Passive Resistor
Active Resistor (overt)
Active Resistor (covert)
Saboteur
Terrorist

CHANGE REQUIRING INNOVATION	Encourage, thank, praise, involve in specific projects, act as parent champions to help engage others. Manage expectations of involvement and influence in decision making.
ROUTINE CHANGE	To move these to the Collaboration Zone: Talk regularly to them on the playground – targeted and positive conversations by teachers and SLT becomes the norm; build confidence and offer "responsibility" e.g. parent ambassador role, parents focus groups; personally invite to specific events; find reasons to involve; get to know them and make them feel comfortable in school; send Dojo/text messages to thank them for attending events.
CHANGE STALLED requires turnaround	To move these to the Co-operation Zone: Use strategies as above plus...Make positive phone calls home e.g. "Friday phone calls" which are personal and positive about their child's learning – this can be by teachers and SLT on a rolling programme of 1 or 2 per week; be nice! – kill them with kindness!; invite them to events which are sociable, informal and comfortable – perhaps when they are already onsite e.g. during bedtime stories; offer refreshments; plan "child as teacher" events to draw them in for their child; provide personal texts for reminders for these events; give them time and listen to issues.
FAILING/FAILED requires radical recovery	Use strategies as above plus... Recognise that these may need to be managed carefully and you may not be able to move these to the Co-operation Zone. Remain professional, keeping communications to the essential. Seek advice and support.

Image 13: Hanna's presentation slide re moving parents (Hanna, 2021)

In Hanna's framework, the categorisation of parents determines the way that the professionals engaged in their child's education should respond to them, within an aim to move them up through the different coloured zones, wherever possible, creating champions and supporters. Champions are to be praised, whilst also their expectations of involvement should be managed, whereas saboteurs and terrorists need to be managed carefully, with only essential communications. Employment of this framework limits the type of relationships that can be created and is potentially more likely to reinforce the behaviours that have apparently been evidenced, due to the specific approaches being taken by educators.

As I have already discussed in Chapter Five, the 2014 SEND reforms purported to put children, young people, and their families at the heart of the SEND system. Although the terms were not clearly defined, co-production and parent participation should underpin every aspect of the SEND system (DfE & DHSC, 2015). As Lamb (2023:3) explains, there were 'at least three distinct strands in the drive for greater parental engagement and co-production with parents and children and young people with SEND in recent education legislation and practice', namely:

> 1) a conscious 'move away from paternalistic models' of parent engagement;
>
> 2) a focus on co-production to bring about 'efficiency and effectiveness'; and
>
> 3) a 'values dimension' that recognises the 'moral right' of parents to have greater knowledge and choice.

However, aspirations for greater parental engagement have failed to materialise and parents report that the system continues to be confrontational, which is reflected in the exponential rise in SENDIST tribunal cases (Green & Edwards, 2021; Moore, 2023). As Green & Edwards (2021:143) describe, parents 'rarely' feel that they are 'treated as equals, perceived as experts or informed'. In contrast, parents can be seen as 'trouble-makers' and are often regarded by professionals as being 'part of the problem' (Green & Edwards, 2021:143).

Whilst Hanna's framework might appear to be an extreme approach to working with families, she is not alone in terms of education practitioners openly labelling or categorising parents of disabled children. Corby (2018), a school SENCO[51], described how parents of disabled children might fall into three categories of 'challenging' parent, namely: the 'angry parent', the 'pandering parent', and the 'non-engaging parent', from which she set out suitable strategies for working with them. Similarly, Elley (2022) describes some parents as having 'blazing keyboard syndrome' before giving her recommendations as to how to deal with 'keyboard warriors'. Osborne (2023) suggests there are four categories of SEND parents, namely the 'pressure' parents, diagnosis-seeking parents, parents who are in denial and the 'dishonest' parents, before also providing engagement strategies to fellow educators which will help them improve relationships with parents. Whilst these are likely to have been produced with good intent, as a way of improving relationships with parents of disabled children, unfortunately parents rarely emerge from these educator produced frameworks in a positive light. However, the professionals who are producing these categorisations and

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[51] Special Educational Needs Co-Ordinator – the teacher who is responsible for co-ordinating additional support for pupils labelled as having SEND. They provide guidance and support to the staff team, co-ordinate assessments and the delivery of provision, and are the main liaison for parents/carers when discussing SEND related issues.

strategies for working with parents are not doing so in isolation. Indeed, there is a long history of both mother blame and labelling, as I now go on to discuss.

9.2.2 The mother who is 'to blame'

Mother blame related to disabled children is nothing new. As Sousa (2011:211) describes, it 'is a centuries-old concept'. For example, in the 16th and 17th centuries, as Braidotti (1999:296) describes, the '"imagination" hypothesis' suggested that mothers had 'the capacity to undo the living capital she is carrying in her womb' because 'the power of her imagination is such that she can actually kill or deform her creation'. The birth of such a 'monstrous' baby – ie. a disabled child – was historically seen to emerge from the guilt or sin of its mother (Braidotti, 1999). Distraught or 'hysterical' expectant mothers were seen to cause their baby's disability, as could those who thought 'ardently about, dream of, or quite simply long for, certain foodstuffs or for unusual or different people' (Braidotti, 1999). Disabled children were seen as 'maternally marked', as the mother's 'imagination, frights, or longings can be transferred to her unborn child, thereby imprinting the child with characteristic marks or deformities' (Wilson, 2002:2). Skin markings and physical differences on newborns 'were read as signs of stigmatizing and ostracizing deformities, leading children to be classified among the *Homo monstrous'* (Wilson, 2002:9, original emphasis). The mother was considered to be able to 'direct the fetus [sic] to normal development or she can de-form it, un-do it, de-humanize it' (Braidotti, 1997:70). Midwives would then use these 'marked' children to frighten pregnant women, warning them of the need to remain alert to potential harms during pregnancy. It is argued by Wilson (2002) that these warnings were precursors to later prenatal care initiatives, which require a focus on the mother maintaining good habits. The popular belief of maternal imprinting was sustained throughout the nineteenth century, even though many expectant mothers experienced either longings or frights during pregnancy without producing a ‘marked’ child (Wilson, 2002).

As Gabel & Kotel (2018:180-1) describe, mothers today continue to be held accountable for producing the ‘perfect baby’ and if a disabled child is born, both the baby and the mother’s personhood becomes ‘diminished’. Raphael (1975:66) describes the time of ‘mother-becoming’ as ‘matrescence’, when a woman changes from a girl or wife into a mother. Matrescence results in changes to her physical state, her status, her emotions, her relationships and her identity (Raphael, 1975). For mothers of disabled children, however, this new identity as a mother can be a stigmatised identity, as she is positioned outside of what it means to be a ‘good mother’ (Douglas et al., 2021:45). As Landsman (1999:135) describes, the ‘same woman whose body held a “person” in the womb may later find herself the (diminished) mother of a “less than full person”’ on giving birth to a disabled child. She is a ‘flawed woman’ who failed to produce a ‘normal child’ (Gabel, 2018:559), and as such she needs to learn how to engage as a mother to a ‘baby belonging to the “outgroup” of society’ (Harvey, 2015:99). It is suggested that a ‘morally responsible’ woman would take necessary steps to prevent the birth of a disabled child (Landsman, 2005:124), in a society where ‘disability is widely perceived as preventable by mothers’ resolute adherence to medical direction’ (Sousa, 2011:223). Mothers become accountable for their ‘failure’ to produce a ‘perfect’ baby, and instead of being seen as valuable contributors to society, they become associated with the categorisation of being a bad mother (Landsman, 1999:141)[52]. It is argued that women become valued as mothers when their children are valued (Gabel, 2018).

9.2.3 The ’bad’ or ‘mad’ mother

Bad mother theories are often deployed in relation to narratives about the production of future citizens (Runswick-Cole & Goodley, 2018; Zeavin, 2021). Although motherhood ‘is a social function of the utmost importance since it ensures the renewal of generations’ (Portier-Le Cocq, 2019:1), disabled children ‘who do not conform’ to expectations of independence and being a future productive citizen are ‘viewed as a “social problem”’ (Green, 2007:151). As Platt (2023:375) describes, ‘the success of the child is perceived to be based on the success of the mother’. Indeed, it is mothers who are criticised for their parenting abilities more than fathers, as they are more likely to take on the primary caregiving role (Stober & Franzese, 2018). Mothers are frequently categorised as ‘good’, ‘bad’, or ‘impaired’, depending on what they do and their life circumstances (Portier-Le Cocq, 2019:8). The ‘good mother imagery’ lends itself to the notion that only ‘bad mothers rear bad children’, while good mothers are seen to rear ‘healthy and emotionally secure children’ (Sousa, 2011:221-2). These ‘culturally-laden terms’ can significantly influence a mother’s sense of self and how they are perceived by others (Knight, 2013:662). Gabel (2018:557) suggests that when a woman ‘mothers a disabled child, her status as mother is diminished’.

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[52] This reminds me of the time when an orthoptist told my daughter and I, during a routine eye examination, that if she found out her baby had Down syndrome, she would have aborted the pregnancy. To this day I do not know why she felt this was a suitable comment to make.

She may 'sit outside the circle of belonging[53]' and given that she 'cannot be the good mother, she is no mother at all' (Gabel, 2018:557).

As well as the 'bad mother' label, as Douglas et al. (2021:39,48) describe, there is also a long history of the pervasive 'mad mother' figure in the global North[54]. Although the imagination hypothesis discussed above is no longer in common parlance, mothers of disabled children have continued to be blamed for their child's disability in more recent times, for example Bettelheim's hypothesis that autism resulted from 'refrigerator' mothers who were 'cold intellectually' (Silverman, 2012:87) and therefore they 'produced autistic states in [their] children with [their] ineffective and underaffective parenting' (Zeavin, 2021:54). Or, in contrast to the mothers who were too cold, some mothers were seen as too 'hot', as 'mothers who mother too much', either 'too permissive' or 'too attentive', resulting in children who were pathologized because of their 'hyperanxious', over-bearing 'smother' mothers (Zeavin, 2021:59,61). Mothers of disabled children are often seen to be '*unreasonable'* by professionals (Douglas et al., 2022:5, original emphasis), whether this is because they are perceived as being 'grief stricken or in denial' about their child's diagnosis, angry and not able to cope (Douglas et al., 2022:5-6), they are unable to control their child's behaviour or they are making '"unreasonable" demands on strapped education and health care systems' when seeking support for their disabled child (Douglas et al., 2021:40).

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[53] I discuss belonging further in Chapter Eleven.

[54] The Global North consists of the world's developed countries, whereas the Global South consists of the world's developing countries and least developed countries. It is not a reference to a geographic region but to the relative power and wealth of countries. It includes UK, USA, Europe, Australia, Israel, South Africa, and others.

These categorisations of mothers of disabled children can be seen within the wider discourse that surrounds the current SEND Reforms, which suggests that some, if not all, of the SEND crisis is because of some parents demanding too much, leaving others vulnerable and without the support they need (Harris, 2024). It has been suggested that the SEND crisis is caused by raised parental expectations and parents pushing each other on to apply for EHCPs that maybe their child does not need (Tirraoro, 2019; Filmer, 2024). For example, with one Local Authority Councillor stated that parents are '"swapping tips" to "fool" trained medical professionals' to secure an EHCP, with action needed instead to address 'parenting skills shortages' (Filmer, 2024).

A new 'particularly pernicious story about England's special needs crisis' has started to emerge, one that has recast the issue as parental 'demand' where 'sharp-elbowed' parents are taking more than their fair share, leaving deserving families without the support their child needs (Harris, 2024:paras 4-5). Current Secretary of State for Education, Gillian Keegan has described what she calls the 'tribunal factor' as a problem, where too many parents are 'taking councils to tribunal to get to a particular school, normally an independent school, normally very expensive independent schools', which she further argued means that 'not only has it put the costs up, but it's a tale of two outcomes, you know Some [sic] people are getting this service with a great school, and some are not getting hardly anything, hardly any support' (Whittaker, 2023:unpaginated). The narrative is that wealthy articulate parents[55] are gaming the system to get more than their child needs (Hill, 2023), leaving other families disadvantaged without suitable provision (Bryant et al., 2022).

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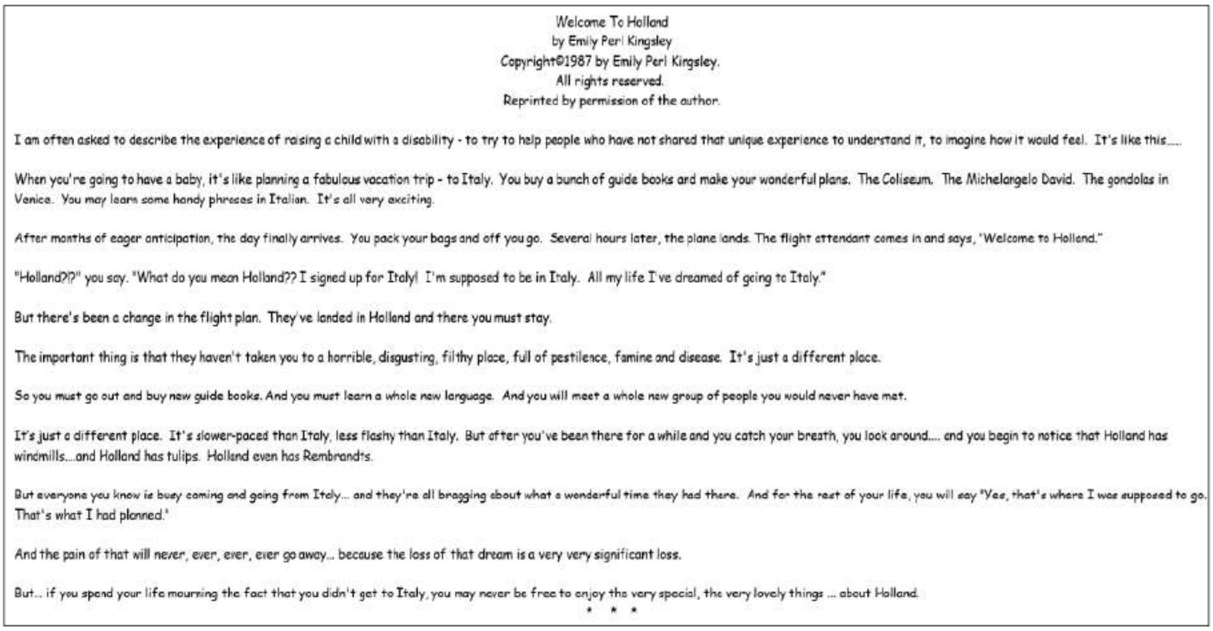
[55] A likely euphemism for middle-class parents with greater social capital.

In a recent discussion about home to school transport, Michael Gove (Secretary of State for Levelling Up, Housing and Communities) echoed these sentiments stating that he ‘recognised councils have a difficult job to distinguish the “deserving” cases “rather than those with the loudest voices, or the deepest pockets, or the most persistent lawyers"’ (Calkin, 2023). Within this pervasive narrative, mothers of disabled children are either positioned as ‘difficult’ (Long, 2023:41), engaging as ‘warrior’ parents (Ryan & Runswick-Cole, 2008:204) battling to secure their child’s rights to the detriment of others, or as ‘vulnerable and in need of support’ (Allred, 2015:49). Either way, mothers are a problem that needs fixing and are pitted against each other too in a battle for limited resources (Minting, 2023). A battle that is not of their making.

9.2.4 The ‘grieving’ mother

In a society where ‘motherhood has become associated with valued children’, the birth of a disabled child who is seen as having ‘diminished personhood’, leads to both the child and the mother being positioned negatively and othered (Lalvani, 2011:278). As Lalvani (2011:278) describes, mothers of disabled children are ‘often placed in a moral category that is separate from other mothers’. They are no longer *just mothers,* instead they must navigate a range of socially constructed identities and expectations that are presented to them. However, as Harvey (2015:99) describes, mothers can also have ‘preconceived notions and uncomfortable feelings of disability according to society’s view of disability as non-normative’. Disability-related discourses are often framed according to the medical/deficit model which represents a disabled child 'not as a person but as a problem', and this impacts on how mothers of disabled children are represented too (Piepmeier, 2012:unpaginated).

Expectant parents are likely to have imagined what their future as a family might look like, ideas that will be shaped by dominant narratives about the 'proper family' (McLaughlin & Goodley, 2008:329). However, the birth of a disabled child can 'shatter the presumed certainty of such possible futures' (McLaughlin & Goodley, 2008:329), which can be unsettling and can cause anxiety. Some parents describe 'grief over losing the ''child of their imagining''' (Green, 2007:155) and the need to 'reorient their future expectations' (McLaughlin & Goodley, 2008:329). This process is described within in the well-known essay by Kingsley (1987) *Welcome to Holland* (reproduced with the author's permission below), which is often sent to new mothers by well-meaning friends and family following the birth of a disabled child, especially a child who has Down syndrome.



Welcome To Holland
by Emily Perl Kingsley
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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

* * *

Image 14: Welcome to Holland

Kingsley wrote the essay for a new mother she was supporting, who found it helpful and shared it others, before ‘it "took wing" and got a life of its own’ (Kingsley quoted in Seidman, 2011)[56]. She suggests that having a disabled child brings ‘certain gratifications’ but also ‘there are certain painful parts that never go away’, including ‘the loss of the dream’, that is, the planned trip to Italy (Seidman, 2011). This links to a common narrative, as discussed by Ryan & Runswick-Cole (2008:203) where having a disabled child is unexpected and undesired by many mothers, therefore they end up on ‘a journey on a different route to that anticipated’. Previous ways to make sense of the world and guiding norms become irrelevant when mothering a disabled child, which is often seen as a ‘fundamentally’ different experience (Ryan & Runswick-Cole, 2008:203). The birth of a disabled child is frequently presented as an ‘unmitigated hardship for a family’ (Lalvani, 2008:436). Underpinned by the 1969 Kübler-Ross model of grief, parents of disabled children are frequently seen to ‘ideally’ move through ‘five stages: denial, anger, bargaining, depression, and acceptance’ after their child’s birth or diagnosis (Allred, 2015:47). It is suggested that many parents:

> grieve with the same emotion and intensity often experienced when a loved one dies. This intensity of grief is normal, because parents often are mourning the death of the child they had envisioned having and the dreams attached to that child (Marshak & Prezant, cited in Seligman & Darling, 2007:185).

Accordingly, professionals are encouraged to understand family responses as a response to crisis so that they can intervene appropriately (Seligman & Darling, 2007).

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[56] This is just one example of the powerful messages that get passed on between generations of mothers in relation to having a disabled child, some of which are printed and others are stories told orally.

Educators in many Western nations often rely on this well-established 'grief model of parental response to disability' which was traditionally 'incorporated into the professional development of teachers' (Allred, 2015:46-7). These ideas can still be seen, for instance in a recent chapter designed to be read by SENCOs about ways of working with families where Green & Edwards (2021:143) describe how parents may be experiencing 'chronic sorrow' because of the 'loss of the hoped-for child' and the 'reality of the life their child will be living', something they go on to describe as 'a living loss'. A further example of the journey metaphor incorporating messages of grief and loss is a paper by Aumann & Britton (2013), which informed the approach to parent participation within the Children & Families Act 2014. The report describes parents going on a 'unique' journey where:

> - Following a diagnosis, there will be a period of grief and sorrow and a sense of 'powerlessness' and isolation, as parents enter into 'unfamiliar territory';
> - This is followed by the emergence of developing understanding of the child's needs, which can result in stress and confusion, as parents attempt to navigate complex systems and try to 'fit into the community';
> - And finally, the family can reframe 'normality' and develop their own expertise and connections, which results in a minority going on to campaign for other families
>
> (Aumann & Britton, 2013:17).

Grief continues to be a persistent narrative, both relating to diagnosis and as an ongoing and recurrent grief about the loss of 'what *might* have been' (Brown, 2016:117, emphasis added). Here grief is ‘linked with anticipation’ of the future[57] (Brown, 2016:119). Inherent in this is an understanding of disability as ‘deficit’ and parents of disabled children being ‘dysfunctional, suffering, or powerless’ (Allred, 2015:47). The grief model therefore brings a set of assumptions about how parents are feeling about their child and how professionals should respond to them, for example parents might be perceived as ‘vulnerable and in need of support, rather than as an equal partner in a truly collaborative educational relationship’ (Allred, 2015:49). As Allred (2015:49) describes, the more parents show frustration or anger or push to have a say, the more they might be seen as being at a particular stage in the grief cycle. The parent’s position can become further marginalised as a result, as their emotions and perspectives are explained away as a grief response rather than a response to a hostile system.

There is, however, little empirical support for the original Kübler-Ross model, never mind its application to the birth or diagnosis of a disabled child (Allred, 2015). It is also important to note that the conditions that construct and sustain this apparent grief, ‘remain largely unexamined’ (Lalvani, 2013:277). During pregnancy, it is suggested to expectant mothers that disability is ‘unlikely, undesirable and to be avoided at all costs’ (Gregory, cited in Ryan & Runswick-Cole, 2008:202), and giving birth to a disabled child is rarely, if ever, mentioned in baby manuals and NCT classes[58]. Expectant mothers are exposed to discourses and practices during pregnancy which suggest that life with a disability is not to be desired and any rejection of prenatal genetic testing is positioned as an irrational choice; mothers are

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[57] I return to a discussion of temporality and the future in Chapter Eleven.

[58] National Childbirth Trust - charity that supports people as they become parents. They offer antenatal classes where expectant parents can learn about what to expect during birth and looking after a new baby.

expected to want the ‘perfect’ child, whereas the birth of a disabled child is positioned as a ‘tragedy’ or ‘loss’ (Lalvani, 2019b:4). Following the birth, new mothers are often presented with incomplete, incorrect or wholly negative information by professionals, who paint a gloomy picture of what the future might look like (Lalvani, 2008). Parents are subject to messages of condolence, or looks of shock or pity, alongside questions about whether they ‘had known’ about their child’s condition, with the implicit messages that if they did know then they should have made a different choice (Lalvani, 2019a).

It is therefore important to recognise that mothers of disabled children are not immune to patriarchal, ableist and neoliberal discourses, including notions of what it means to be a ‘good’ mother (Runswick-Cole & Ryan, 2019). Ableism is when ‘able-bodied-and-mindedness is framed as a market of human worth’ (Goodley, 2023:170). As Goodley et al. (2014a:981) describe, ‘neoliberalism provides an ecosystem for the nourishment of ableism, which we can define as neoliberal-ableism’. This ideology of neoliberal-ableism upholds a dominant cultural imaginary that ‘values the mobile, self-sufficient, responsible, accountable and flexible normative citizen’ (Goodley, 2023:176). Individuals are expected to adhere to ableism’s ideals, and disabled people – and their parents – are required to embrace ableism to ‘overcome their disabling conditions’, to not just survive but also to ‘thrive’ (Goodley et al, 2014a:981). We live in a ‘deeply disablist and ableist world’ (Goodley, 2023:179), a world full of ‘messages that to be disabled is to be less than, a world where disability may be tolerated but… is inherently negative’ (Campbell, 2009, original emphasis).

Campbell (2009:17) argues that we are all ‘shaped and formed by the politics of ableism’ and are subject to ‘the phenomena of internalised ableism’. She suggests that ableism is ‘embedded deeply and subliminally within culture’ (Campbell, 2009:19). Process of internalisation are complex and disabled people, and their parents, are engaged in a ‘constant negotiation with competing responses to disability (both positive, negative and contradictory)’ in which they can at times unwittingly become complicit, ‘reinforcing impairment as an undesirable state’ (Campbell, 2009:27-8).

Mothering a disabled child takes place within historicised power structures and constructions of what it means to be a good mother, which feed into ideas of loss of the imagined future as ‘motherhood is interrupted by disability’ (Gabel & Kotel, 2018:180). Both the mother and her newborn may also miss out on the normal ‘markers announcing personhood’ such as celebrations and birth announcements (Gabel & Kotel, 2018:181)[59]. It is therefore unsurprising that the grief narrative persists, including within education. Unfortunately, as Allred (2015:53) describes, most educators ‘have been socialized for decades to perceive parental response to disability through the grief lens’ which means that they will find it hard to move beyond this model to accept a more nuanced understanding of parental responses to disability.

As disabled children progress towards starting school, notions of ‘otherness’ are ‘institutionally upheld and reified through the existence of the parallel systems’ of mainstream and specialist education (Lalvani, 2019b:4). The education system is predicated on ableist and neoliberal demands, and disabled children have their deficits in bodies and

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[59] I recall a friend calling me after my daughter was born and her first words were ‘I am sorry!’.

mind assessed and recorded, and these are used to ascertain which type of education they should receive. As Goodley (2014:104) explains, ‘the neoliberal, ableist student is the ego ideal of the educational system, undergirding forms of teaching, learning and assessment, [meaning that] many dis/abled students fail to match up to this simulacrum of a pedagogical subject’. Mothers are only too aware of how their disabled child is positioned within the education system but may be less aware of how they have internalised ableist attitudes themselves. Davis (2002:148) suggests that ‘we barely know we are ableist’.

As Daniels (2020) describes, ableism can infiltrate our thoughts and ideals, due to its pervasive nature. Accordingly, mothers of disabled children can be complicit in perpetuating ableist discourses and practices, as they feel compelled to emulate ‘normal’ as much as possible. Both disabled children and their mothers can feel constantly under surveillance and judged to not be good enough, due to the internal critique that they carry with them (Daniels, 2020). Ableism becomes internalised and ‘part of our un/conscious everyday lives’ (Goodley, 2014:32) and although it is possible to do, it can take significant levels of emotional labour to ‘push back against the unspoken rules and regulations of ableist normativity’ and the expectations that are placed on us to become society’s version of ideal (Daniels, 2020:239).

9.2.5 The ‘good’ or ‘warrior’ mother

Parents of disabled children do not want to be perceived as victims (Van Hove et al., 2009). As suggested above, one of the positions that parents of disabled children might take to reframe their situation away from the grief model is by recognising their situation as a new normal (Ryan & Runswick-Cole, 2008). This can be seen in other research findings, for example Thomas (2020) discusses how families attempt to offer alternative narratives to the tragedy or grief narratives, as parents say that they are lucky, blessed or proud to have their children, who have had a positive impact on their families. They want to position themselves and their children as ‘normal’ as they attempt to dismantle stereotypes and push back against stigma (Thomas, 2020:458). Here, mothers of disabled children are transformed from ‘fearful and grieving caretakers to open and accepting parents’ who have constructed ‘new conceptions of mothering and normalcy’ (Sousa, 2011:229). Mothers might present the presence of disability in the family as leading ‘to a richer and more meaningful life’, where parenting is ‘richly rewarding’, enabling the mother to ‘project an identity as a “good mother”’ (Knight, 2013:666).

A disabled child can also be positioned as a ‘blessing’ that has provided the mother with the opportunity to transform herself into a better person (Knight, 2013:667). Landsman (1999:142) suggests that this shifts mothers from ‘being defined as a careless producer of a defective product to a purposefully chosen recipient of a special gift’, an act of othering that shifts from the mother’s actions which she can be blamed for, to ‘what she is’, ie. someone special. These conceptions of mothers of disabled children are frequently simplistic and, as McLaughlin & Goodley (2008) describe, bear little similarity to how parents experience or negotiate disability knowledges and identities in their lives.

Moving away from any suggestion of devastation or loss, mothers can also be positioned as the ‘heroic carer’ or ‘super-parent’, suggesting strength and resilience (Brown, 2016:114-5). This narrative is common in memoirs written by mothers that position themselves as being heroes with ‘superhuman strength’ who are on a ‘quest’ to secure the therapies and support their child needs (Sousa, 2011:228). However, Gabel argues, the ‘pedestal’ that the mother stands on ironically places the mother ‘above other mothers’ whilst simultaneously reducing both her status and that of her child (Gabel, 2018:558). This is still a stigmatised position that others would rather avoid (Gabel, 2018).

Furthermore, mothers are expected to ‘smile’ and demonstrate ‘unfailing dedication’ to their child, without complaining (Gabel, 2018:559), which can result in mothers managing or hiding their own feelings. Her emotions must be repressed, and weaknesses hidden, otherwise she might be seen as selfish, which can lead to further scrutiny (Ryan & Runswick-Cole, 2009). Although anger might be a justified response to the injustices faced by both mother and child, this also does not fit with the ideal of being a good and selfless mother. Yet anger or other emotions can be a position from which mothers can ‘bear witness’ to their ‘marginal social location’ (Gabel, 2018:562-3), giving a sense of authority from which she can speak out.

There are many other labels or metaphors that might be used by parents of disabled children to ‘consciously and purposefully’ position themselves in a certain way ‘to protest against the defectological/deficit discourses used by some professionals (and their systems) for their children' (Van Hove et al., 2009:197). This includes the 'warrior' parent on a 'warpath' to fight for their child's rights, the 'strategist' who seeks allies and acts strategically after thinking things through first, the 'tight-rope walker' who seeks to balance '"normal" and "special"', the 'trainer/teacher' who seeks to teach others about their child's diagnosis and their experiences, or the 'bridge builder' who tries to bring people together to support their child (Van Hove et al., 2009:194-197).[60] Lalvani & Hale (2015) describe how some parents describe themselves as 'adversaries' who are avoided or disliked by professionals; they draw on 'combat-related metaphors such as "being armed," "having ammunition," or "pulling out the guns"' (Lalvani & Hale, 2015:29). Some might even go as far as wearing clothes that articulate their identity as a SEND Warrior, for example this t-shirt produced and offered for sale by the owners of parent-led website Special Needs Jungle[61]:

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[60] It should be noted that Van Hove et al. (2009) point out that whilst parents might use these metaphors, they are not necessarily pinning themselves to one particular position when doing so.

[61] Of course, the reference to 'jungle' here is also indicative of parents having to struggle through a difficult terrain.

Image 15: T-shirt on sale with Special Needs Jungle

Despite these metaphors and positions being considered as acts of resistance, it is important to note that celebrations of diversity or the rejection of normative expectations can also be seen as further examples of ‘unreasonable behaviour’, and non-compliance or rebellion can be seen as evidence of ‘madness’ (Douglas et al., 2021:47). Parents who present more positive constructions of disability are seen to be ‘denying reality’ or ‘deluded’ (Ryan & Runswick-Cole, 2008:200). Also, labels such as ‘agitator, warrior, difficult parent’ are used to both ‘valorise and vilify’ mothers (Runswick-Cole et al., 2022:314). For example, then Children & Families Minister, Edward Timpson, referred to some mothers as ‘agitators’ when talking to SENCOs in 2017 (It Must Be Mum, 2017). As Douglas et al. (2021:52) describe, any resistance ‘can feel futile when it is merely re-inscribed back into the dominant narrative and used to re-affirm the madness of the non-compliant mother’.

Further, Sousa explains how whilst the ‘warrior-hero archetype’ might appear to provide a more positive construction for mothers to engage with, it places the responsibility for mitigating the impact of the impairment on the mother, whilst ‘neither alleviating the social burdens’ nor diminishing ‘exposure to systems of inequality’ (Sousa, 2011:221). It might move closer to the idea of the ‘good’ mother who will work hard to access resources for their child, but it does not necessarily enable a shift away from mother blame (Sousa, 2011). As Runswick-Cole & Goodley (2018:236) describe, ‘mothers of disabled children are still held to account for their children’s development and behaviour’.

When mothers are seen to be at blame for issues relating to their disabled child, they can become subject to greater levels of intervention (Clements & Aiello, 2021). Mothers of disabled children often feel ‘under surveillance’ as they need to ‘establish themselves as “good mothers”’ (Knight, 2013:665). Accordingly, they are required to demonstrate the ‘unflinching demands of selflessness’ that have been imposed on them (Carey et al., 2020:9). Those who fail to live up to the ‘ideal model, the canon of caring, loving, invested, sacrificial mother’ who is not ‘too pushy’ are also labelled as a problem requiring fixing (Portier-Le Cocq, 2019:5). Of course, if a mother fails, despite exhaustive efforts, to secure services for their child, the warrior-hero depiction fades, and shifts quickly back to mother-blame (Sousa, 2011:235). As Gabel (2018:557) describes, mothers of disabled children are either positioned as ‘pushy and aggressive or not pushy enough and not aggressive enough’. Mothers of disabled children cannot win when attempting the ‘delicate balancing act of good mothering’, and it can feel at times as though ‘they never do the right amount of anything’ (Gabel, 2018:557,561).

9.2.6 The ‘activist’ mother

As discussed in Chapter Four, the idea of mothers of disabled children becoming activists is not new. As Sauer & Lalvani (2017:54) describe, ‘there is a long tradition of family and grassroots activism in the history of the education of students with disabilities’. Parent activism emerged in the 1950s (Carey et al., 2020). Carey et al. (2020:138) suggest that this is because the political climate changed after World War II, as social activism grew and ‘varied groups jockeyed to access and control’ resources being made available. Other emerging political movements of the time no doubt made mothers aware of the opportunities to start demanding their rights. Darling (1979) coined the term ‘parental entrepreneurship’, suggesting that parents who previously felt helpless started to push back against ‘professional dominance’ and became ‘ripe’ for activism and advocacy. Mothers who were ‘constantly having to present an alternative view of their child to the world’ started to recognise their subordination and instead of wanting to just argue for their child, they sought to transform society’s understanding of disability (Pannitch, 2008:8).

Darling further suggests that some mothers, went on to become ‘crusaders’, acting as ‘reformers’ or ‘revolutionaries’, on a quest for equal rights and attempt to establish services that do not yet exist (Darling, 1979:226). Mothers not only wanted to campaign for their own child’s rights but also wanted to be recognised beyond the narrow maternal role expected of them (Pannitch, 2008). Alongside disability activist groups forming, parent led groups emerged, challenging professional dominance and institutional care. Pannitch (2008:7) suggests that mothers become activists when their ‘“polite” attempts to secure services for their children failed’, meaning that they need to develop ‘new and stronger tactics’. Therefore, some mothers become ‘vigilantes’ who developed ‘special competences’ as they became advocates for disability rights (Stober & Franzese, 2018:76). By working together, parents created a sense of community, shared resources and together fostered ‘a sense of belonging’ (Carey et al., 2020:138). Through this action, mothers were able to carve out ‘a salient positive social identity for themselves, tied to a cause deeply related to their role as parent’ (Carey et al., 2020:138).

This is not without issues though. Mothers of disabled children can often find themselves in a complex and marginal position in relation to the disabled people's movement, as they can be seen as both allies and oppressors (Ryan & Runswick-Cole, 2008; Carey et al., 2020). The goals of parent activists, whilst arguing that they want to improve the world for their child, can 'at times differ dramatically from those of disabled activists' who are operating in the same political arenas, where both are attempting to effect change (Carey et al., 2020:4). There is concern that by amplifying parents' voices, the voices of disabled people themselves will be silenced (Carey et al., 2020; Aspis, 2022). For example, there can be tensions 'when a mother identifies herself as "a mother of a disabled" child but her child does not wish to be identified as a disabled person' (Ryan & Runswick-Cole, 2009:46). Disability scholars suggest that parents are wedded to a medical model of disability, pushing for diagnoses and embracing labels for their children (Ryan & Runswick-Cole, 2008). It is important to recognise, however, that this is the language and approach parents are required to use to secure appropriate education provision for their children, for example the requirement to detail their child's 'needs' within an application for an Education, Health and Care Needs Assessment.

Parents have also been seen to seek separate spaces, eg. specialist education provision, for their disabled child even though the disability community were campaigning for full inclusion[62] (Carey et al., 2020:5). Many disability scholars are concerned that parents are unable to imagine how their child will be included in mainstream schools, and therefore choose a specialist placement (Ryan & Runswick-Cole, 2008). Additionally, mothers can be

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[62] It is important to note that not all disability campaigners will be arguing for full inclusion/mainstream education for all. I do not wish to present the disability community as a homogenous group of people.

seen to ‘pursue paternalistic approaches to care’ such as guardianship or supervision, so that they can maintain input and control, which also can further legitimise the creation of separate spaces for disabled people (Carey et al., 2020:4-5). Mothers of disabled children can therefore sometimes be positioned as agents of exclusion, as they are the ones who make decisions that can lead to their child’s exclusion from mainstream education and society.

Disabled activists, who have rejected deficit discourses of disability that devalue and stigmatise disabled people, have argued that parental stories of disability will often suggest disability is a burden and focus on the parents’ needs and interests rather than offering positive representations of disability (Carey, et al., 2020). Some disability activists believe mothers are ‘agents of disablism’ and as ‘complicit in their children’s oppression’ (Runswick-Cole & Ryan, 2019:1127-8). Although mothers of disabled children have ‘served as effective activists and advocates in arguing for changes in the educational, health care, legal, public policy, and social service systems’ which has been to the benefit of disabled children and adults, it is also suggested that they have ‘contributed to the disablement of adults with impairments when they have bought into the medical model of disability and focused their attention on trying to “fix” impairments rather than accepting disabled children as they are and encouraging them to develop disability pride’ (Green et al., 2016:265). In advocating for support for their child, parents must frequently articulate the ‘problems’ that they or their child are facing, as previously discussed. Some parents might feel that they need to ‘secure a diagnosis or label for their child as a ‘gateway to information, resources and support’ or to counter the charge that they are ‘inadequate or incompetent parents’ (Ryan & Runswick-

Cole, 2008:200). Accordingly, the use and acceptance of a medical approach could be seen as a ‘political act of pragmatism’ (Ryan & Runswick-Cole, 2008:200).

As I go into Part Two of this chapter, I intentionally move away from these current representations of mothers of disabled children, to focus instead on the actions mothers take, rather than who they *are.* I draw on the conversations that took place with the seven mothers to illustrate and illuminate this theoretical discussion in which I provide alternative ways of thinking about the role of mothers of disabled children in education, that resist mothers being seen as the root cause of the problem, and instead recognise mothers in their becoming.


The Treacherous Path
PUSHING BOUNDARIES
Agent of change
Force of Nature
CRAZY
Mum
on a mission
Dreaming of
BETTER
love
war
bringing hope
Step lightly
TO GET TO A PLACE THAT WORKS FOR EVERYBODY
Watch out
A FOREVER WAR BEGINS
in the fight for justice
A tale of two tribes
under threat
ALWAYS ON guard
Has the team finally met its match?
The fight goes on
middle classes are in revolt
An Unwinnable War
Territorial conquest—or reconquest—is not in itself a form of war termination.
WHAT WINNING DOESN'T LOOK LIKE
HOW LONG DO YOU EXPECT ME TO PLAY THIS GAME?'
NEVER STOPS
MEASURABLE DAMAGE
We need you to do it again.
OLD WARS

9.3 Part 2 – Becoming through affordances

> *So, here's the lot of a SEN parent: Option A - keep your mouth shut, take what's offered, watch as your child fails repeatedly in a failed system and try not to think about what tomorrow brings because it's frankly too scary. Option B - fight a broken system for what we know our children deserve and are legally entitled to and risk being called greedy, all in the hope that tomorrow will be better and brighter. Option B for me, every time. My child has given me so much; not least blind determination, a strong moral compass and very thick skin!* (Clare)

In Part One of this chapter, I discussed how mothers of disabled children are frequently seen as being part of the problem, not least in current official SEND discourse. In line with the theoretical underpinnings of this inquiry, I now move towards thinking about mothers in their becoming. Accordingly, it becomes necessary to think about *moments of doing* rather than trying to pin down who the mother *is.* I will suggest that mothers are engaging in actions whereby they are attempting to make education more habitable for their children. I do this through thinking with the idea of 'activist affordances' (Dokumaci, 2023). Instead of conceiving mothers within categories such as 'activists' or 'warriors', this approach suggests a need to recognise the acts that mothers are performing that might otherwise 'go entirely unnoticed' yet are important acts of 'world-building' (Dokumaci, 2023:5). This 'invisible work' is often required to be undertaken by those who 'do not fit' and therefore must 'work harder to compensate for this lack of fit' (Giraud, 2019:36). Mothers of disabled children undertake this work through love for their child, potentially feeling that they are the 'only person on this earth who truly cares enough' about them (Green & Edwards, 2021:141) to make education more hospitable and inclusive.

Dokumaci (2023:5) describes activist affordances as ‘performative microacts/-arts through which disabled people *enact* and *bring into being* the worlds that are not already available to them, the worlds they need and wish to dwell in’ (original emphasis). This is a mode of activism that demonstrates ‘how to build worlds with acts’ (Dokumaci, 2023:5). Everyday acts of world building both ‘make up’ and ‘make up for’ the affordances for disabled people that have failed to materialise within the environment that they are occupying (Dokumaci, 2020:98). As I will discuss, mothers of disabled children can be seen to perform such acts of world building, attempting to make education a less hostile place for their child, at the same time as supporting other mothers to perform similar acts too. By focussing on what mothers *do* in specific encounters, rather than who they are, it can draw attention to the other elements, both human and non-human entities, that co-constitute the event. This allows us to move away from static conceptions of mothers that categorise as either good or bad mothers, instead drawing attention to the acts that are performed by mothers who find it necessary to engage on their child’s behalf in a complex and hostile system. This is not to suggest that mothers of disabled children will always act in ways that promote inclusion or that are in line with disabled people’s activism. As I have already discussed, mothers can be caught up in discourses of ableism which impact on their own self-identity and their actions. Disability affordances enables a framing of mothers’ actions as world building. Therefore, it can be seen that maternal subjectivity and how mothers understand their role can impact the choices they make and the futures that they believe are viable, which will determine the worlds that subsequently become possible for their child.

I didn't used to be like this.
Cynical
How can I be that parent?

Keep your mouth shut
Take what's offered.

I'm pushing back,
Refer them to the EHCP checklist
Made a self-referral
Met with my MP
Emailed the teacher, went to the Head
I put in all capital letters
CALL ME NOW!!!!
I'm trying not to get cross.

Take a deep breath
Think... right, okay!
I will have the headspace, do all the paperwork
Get ready
Be prepared.

Have I done enough? I question myself.
A whole lot of guilt
Probably a bit too worried
Really should have been more feisty
An emotional rollercoaster.

I gave up work
Gave up a whole part of my life
Got to prioritise, only so much headspace
So overloaded
Keep making silly mistakes
Exhausted, overthinking
People don't see
Take it literally one day at a time

Have to strategize
Suppress my feelings try not to get cross!
Be compassionate
Sat in meetings, primed
Heavy heart
Fixed smile
Cannot fall out with these people
Desperately worried
I want them to step up
Need more communication
Oh no! A nightmare parent!

Overwhelmed
I have really struggled
Hundreds of hours of my life
Have I done enough? Don't guilt trip me please.

I can't write any more.
What's the point?
Why have we even fought for this?

Transcript Poem 'How can I be that parent?'

9.3.1 An exhausting and time consuming engagement

Pupils who are disabled and labelled as having SEN are subject to a separate legislative framework, in addition to the main education legislative framework, as are their parents. Processes, such as school admissions, are different. Mothers of disabled children cannot just expect that their child will go to the local school and be accepted there without question, instead they are required to go through complex and lengthy EHCP assessment and review processes, where professionals submit 'evidence' which is used to set out the pupil's Special Educational Needs and the provision that is assessed as necessary to meet these needs[63]. Sitting alongside the legislation, the SEND Code of Practice sets out what roles each party, including parents, is expected to undertake and the associated timescales[64]. Jayne explained in our first meeting that she did not know that there was a different process for school places, and therefore '*I was just waiting for my letter to arrive, and nothing arrived*' which led to the realisation '*Okay, we are really different. We don't even have a school place, we're so different'*. These separate processes immediately set parents apart from other parents within education, as they and their children are treated differently.

During the conversations that took place within this inquiry, it was overwhelmingly clear that the mothers' engagement with the education system is different to that of mothers of non-disabled children. At one point, Clare described how she was operating within a '*hostile environment'* when discussing her engagement in the EHCP process. The language of 'fight'

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[63] I discuss this more in Chapter Ten when discussing documentation.

[64] Though these are frequently not adhered to by local authorities (Long & Roberts, 2024:37).

and 'battles' was frequently used by the mothers, for instance by Faith who described her need to fight for Brave's '*equal rights to a decent education',* and the subsequent need to '*rest and prepare for a new battle'.* She described having '*an incessant fight against the educational system to make it fair and equal'.* Jayne described a '*big battle with our EHCP'* trying to get Zebedee enough support '*so that he has half a chance of coping in a mainstream school',* further describing how they '*went on this massive fight to get the right support, which was really difficult'.* Anne further described the need to '*pick your battles'.* There was a sense that mothers do not just engage in one 'battle' but there is an ongoing process that is laden with conflict. The mothers in this inquiry were not alone in using the language of battles and fighting, for example Green & Edwards (2021) describe how mothers of disabled children describe feeling 'as though we are constantly doing battle' and having 'to fight for everything (Green & Edwards, 2021:141). Mothers become engaged within a process where 'every conversation, phone call or form that needs filling in becomes part of their battle to get what they need for their child' (Green & Edwards, 2021:143).

It is easy to see why the label of being a 'warrior' or 'activist' becomes attached to mothers of disabled children, as they engage in the process that is experienced as horrendously traumatic and draining. However, despite the language of fights and battles being used, it was clear that the identity of warrior or fighter was not one that the mothers engaged in this inquiry were necessarily comfortable with. Indeed, Jayne described '*I hate even using that word… fight*' and Sita asked '*Oh my god. How long do we have to fight for you know?'.* Similarly, whilst discussing how she recognised the need to fight for your child's rights and had set up a support group to help other parents do the same, Emily also stated how *'I don't* *want to be that, you know, I am not a pushy mother, I don't want to be that problem mum'.* Being in conflict and seen as an aggressor was clearly not something that the mothers wanted to be. Jayne described living in a '*nightmare'* further explaining that it is not '*until you're in the system you realise how awfully complicated it is… it's really hard to imagine'*. Despite this, the mothers clearly still wanted to create a positive and collaborative relationship with their child's school. As Clare also discussed, '*without that cooperation and goodwill the whole process breaks down'*. They also described having to regulate their own behaviours, for example, Jayne mentioned how:

> *as well as being annoyed, as well as being quite angry with them. I was like, yeah, how can I be, how can I be that parent that is pushing for my child but without being too annoying?*

Clare experienced similar: '*We've all sat in meetings with heavy hearts and fixed smiles on our faces when things are not going well because we know we cannot fall out with these people who often go the extra mile for our children'.* It becomes necessary for mothers to mitigate against potential damage to relationships, which could have a knock on effect for their child's education. As Runswick-Cole (2013) explains, mothers of disabled children are required to engage in emotional labour where they manage their feelings, to demonstrate more acceptable behaviours, to protect their children. She describes the need also to perform 'scripted performances' which might limit the range of responses available in any given situation (Runswick-Cole, 2013:108).

A few of the mothers in this inquiry highlighted the sacrifices they felt necessary to make to be able to advocate for their child's education. Anne described how she had been '*getting really stressed at work really, really seriously, really depressed, really anxious'* and so she decided to give up her job. Sita also discussed how she resigned from work due to the anticipation of Kiran's possible exclusion:

> *Because I just dread the September time. Yeah, I'm just gonna get this call. I mean, can you come and then how many times can I get leave from working? Yes. I just thought yeah, just leave work.*

These are significant lifestyle choices that will have an impact on the family, in terms of finances, but also on the mother who will no longer be considered a 'productive' citizen in economic terms. It will also have an impact on how the mother sees herself and how others see her too. Mothers are seen as non-professionals, as 'stay at home mothers', potentially with nothing important to say. Despite being 'engaged in everyday theorising about the lives of their children as they navigate the often hostile waters of education, health and social care' (Runswick-Cole et al., 2022:322), mothers' views are frequently reduced to feelings: 'mum feels' (Douglas et al., 2022:9). Mothers' experiences which are often uncertain and messy are frequently seen as irrational, as views that do not fit, and therefore are considered 'non-sense' (Mercieca & Mercieca, 2016:86). This means that even when mothers attempt to present their perspectives as professional and evidence based, they can still be dismissed. As Emily described, '*I went into the last annual review with the power knowing I was a professional that I held all the cards but still nobody still believed me'*. Accordingly, this can result in mothers undertaking actions to demonstrate the authority of their views, to demonstrate that their contribution is not simply feelings that can be ignored, but valuable knowledge that should be listened to[65].

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[65] Maybe this partially explains why I am doing a PhD and also why mothers engage in research inquiries such as this?

Mothering a disabled child can be time consuming, expensive, and physically exhausting (Green, 2007). Both Emily and Clare described how '*it's a full time job*' to engage in a system that causes anxiety and depression for many. Faith explained '*sometimes I feel that I have lost the battle nights without sleep, I feel that my strength is exhausted, I fear that my requests will never be heard*' and Clare described being '*absolutely spent*' by the tribunal process, which '*was such an emotional, such an emotional thing to go through, to have to constantly advocate for your child'.* She also described how '*it's exhausting. Being on that red alert all the time*'. Emily similarly described how

> *it's just just kind of exhausting. Really. And you know, and I want what's best for him*.

What becomes clear is that these mothers want what is best for their child, and the only way to achieve that is to engage within the SEND system, a system that might purport to put the child and their family at the centre, but one that manifests as being incredibly challenging for many parents to navigate.

Given how frequently exhaustion was mentioned in our conversations, it felt important to explore further about what exhaustion might produce, what it might 'do'. Mercieca & Mercieca (2016:90) suggest that exhaustion 'is a desubjectivisation'. The 'I' becomes decomposed when 'we engage in exhaustion' (Mercieca & Mercieca, 2016:90). Being exhausted allows identities to be disturbed and limits of being to be questioned in the contingency of the encounter, as different bodies 'release new power in their capacity to act and respond' (Mercieca & Mercieca, 2016:91). Braidotti (2019a:18) argues a similar point, suggesting that living in a state of exhaustion can become affirmative, because exhaustion can be 'activated into the generative pre-condition to learn to think differently about ourselves' (Braidotti, 2019a:18). She suggests that there is a 'creative potential' that emerges from exhaustion, where the 'intensity' of discomfort can become 'a motor of change' (Braidotti, 2019a:17). This does not mean disregarding the pain of exclusion – or potential exclusion in the future – but instead recognising how this state of being can lead to more affirmative praxis (Braidotti, 2019a). Allan (2008:18) describes how there 'appears to be an exhaustion among those attempting to cope with the pressures of inclusion' and this can be a 'cause for concern' as it suggests 'closure and defeat'. However, although mothers engaged in this inquiry described being exhausted, none of them were willing to give up on making education more hospitable. They all described the activities that they continued to undertake, sometimes defiantly, to support their child's education, despite it often feeling futile, for example attending specialist training courses, learning the law to support their engagement in the system, supporting other parents (eg. writing blog posts or running a social media group), filling in paperwork and attending events, meetings and webinars.

Braidotti (2019a:175) states that exhaustion 'essentially expresses our capacity to affect and be affected by others'. Accordingly, it can lead to 'generative encounters with others' and transformational acts, as a form of positive power, *potentia* (Braidotti, 2019a:176-7). Drawing on Spinoza, Braidotti (2011:4) describes how power 'is a situation or a process, not an object or an essence'. It is not something that can be given or taken away from someone. Rather, there are two ways of seeing power – 'as restrictive (*potestas)* or as an empowering or affirmative force *(potentia)* and subjectivity is 'the effect of these constant flows of in-between power connections' (Braidotti, 2011:4). It becomes important to understand and 'expose' *potestas* power, which is 'the repressive structures of dominant subject-formations', whilst also recognising the ‘affirmative and transformative visions of the subject as nomadic process (*potentia*)’ (Braidotti, 2019b:34). Potentia – lines of empowering modes of becoming – are not the same as that of being or identity (Braidotti, 2011:42). Potentia offers us alternative ways of cultivating relations with others that are ‘not tied to the present by negation; instead they are affirmative and geared to creating possible futures’ (Braidotti, 2011:286). When we consider power in these terms, it becomes important to pay attention to the ‘micro-instances of embodied and embedded self and the complex web of social relations that compose subject positions’ (Braidotti, 2011:4). From this starting point, instead of seeing mothers as warriors continually fighting within a hostile system, it becomes possible to see them being and becoming in relation, as they draw on their ‘direct experience of the pain of exclusion’ (Braidotti, 2022:117) they become readers of *potestas*. From this position they are able to create new spaces and ways of engaging that are hospitable and inclusive for their child, enacting *potentia*. Potentia is a ‘productive’ form of power ‘that overcomes “places of pain” and seeks agency where it can be found’ (Sidebottom, 2019:232).

Because of their experience of the education system, mothers of disabled children can provide a more lucid understanding of how power works in practices of exclusion (Braidotti, 2019a)[66]. As Braidotti describes, this lived experience can be the starting point for the manifestation of a ‘pro-active activism’ that recognises our ‘shared ability to actualize and potentiate different possibilities’ (Braidotti, 2019a:175). As I will go on to articulate below, mothers of disabled children can often be seen to be enacting creative and affirmative micro-transformations as they engage with the education system, whereby they are employing a

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[66] However, it should be noted here that mothers are also likely to be caught up in discourses of ableism which they might not be conscious of, which can impact on their engagement and understandings of exclusion.

productive ‘*potentia*’ power rather than engaging only in organisational ‘power-as-usual “*potestas*”’ (Sidebottom, 2021:7). The EHCP process is a form of *potestas* power, with limited ways to engage outside of the boundaries of the defined roles and process. When mothers work together to create alternative ways of engaging with the system or enacting their roles as mothers, this can be an expression of potential. When attuning to the emerging enactments of ‘*potentia*’ power, it becomes possible to de-centre and deviate from the dominant narratives that position mothers of disabled children in a negative light and instead to see them as creating ‘new possibilities, playing a role in generating a “de-potentialised space”’ (Mercieca & Mercieca, 2016:92).

9.3.2 Mothers enacting affordance-making

> What if the making of microactivist affordances is not, and has never been, one person’s individual affair? (Dokumaci, 2020:98).
>
> Every single day, your dad carried you? (Dokumaci, 2020:98).

The term ‘disability affordances’ was introduced by Dokumaci (2017; 2020; 2023), as a ‘new way to think through the entanglements of disability, performance, and matter’ (Dokumaci, 2017:394). The concept emerges from materialist reconsiderations of disability, offering a way to theorise about the ‘“failures” of the environment’ to take particular bodies into account (Dokumaci, 2017:394). Dokumaci suggests that this approach neither propagates a medical or deficit view of the body, nor does it ignore the lived realities of impairment for individuals (Dokumaci, 2017). Instead, the focus is on how individuals learn ‘to get through the everyday' with their own affordances (Dokumaci, 2017:395). She describes how disabled people in her own inquiry were seen to develop approaches to banal and everyday tasks, as they live with chronic illness that causes pain and impacts on movement and balance. Affordance-making performances become necessary when there is 'an incompatibility, "a misfitting"' with the material world[67] that causes a rupture where '*a space opens up* for the organism and the environment to re-relate in combinations other than what has so far been thought possible' (Dokumaci, 2017:400, original emphasis). Through these affordances, the mis-fitting individual can be 'made to fit again' because the environment has changed (Dokumaci, 2017:404). Instead of disabled learners needing to 'fit' into an existing educational structure, this approach would allow consideration of the education spaces as unstable and '*always differently possible'* (Dokumaci, 2017:404)[68]. Whilst they might not be intending to do so, actions taken by mothers of disabled children have the potential to transform the educational environment, to make it more inclusive and welcoming of difference. These are not, however, actions that are not always overtly recognised 'activist', but they are actions that have the potential to open up the field of possibility.

As discussed in Chapter Five, the current broader education landscape in UK does not serve all children well and has produced a 'potentially hostile context' for inclusion (Fulcher, cited in Cole, 2005:332). Accordingly, it is often suggested that mainstream schools cannot work for all children (Cole, 2005; Warnock, 2007). To be seen as effective, schools must focus on proxy goals of progress measures and league tables which requires them to achieve targets and strengthen the market position of the school (Ward et al., 2015; Astle, 2017). However,

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[67] I discuss misfitting further in Chapter Eleven when discussing belonging.

[68] This lends itself also the argument presented in Chapter Eleven.

some students are considered a challenge, or a risk, to schools being seen as effective, as they may disrupt the education of others and/or have a negative impact on school results (Slee, 2001; Cole, 2005). Consequently, students may be turned away or excluded from schools to protect school results. Alternatively, students may be included, but within a process of assimilation, where ‘cosmetic amendments to practices and procedures’ are used to include students within the school as it is (Slee, 2001:167). As Cologon (2022:397) describes, these are ‘exclusionary practices’ that are ‘re-named “inclusion”’ without any further transformational change to the setting or those within it. Pupils who have learning disabilities – for instance those who have Down syndrome – can be ‘relegated into a category of the “least possible/desirable/required to include”’ (Cologon, 2022:397), because of their perceived inability to contribute to the school’s standing, and the demand they are seen to make on resources. Their right to be included has a ‘perpetual and demeaning “question mark” attached’, meaning that within the current approach to education their inclusion becomes conditional and a ‘privilege, not a right’ (Cologon, 2022:398).

When a mother of a child who has Down syndrome wants their child to be included within mainstream education, they are likely to meet resistance. Sometimes this is explicit and has a significant impact, as described by Clare who described visiting a potential primary school where:

> *the head teacher crossed her arms. You know, the body language. They really didn't want him. And I said do you have anybody here who can use Makaton? No! Not no, but I'm sure you know… there was absolutely no willingness, and at the end of this tour she said, well I don't know how we're going to fund this*.

Accordingly, Clare visited other schools to find one where Thomas was welcomed. However, sometimes there are more implicit exclusionary behaviours. George described how Ezra is ‘*taken out of a lot of the lessons, rather than, rather than basing it at his level, he's just taken out… he doesn’t do a lot within the class now’.* She explained how he spends all his time with a Teaching Assistant rather than being taught by a teacher and Sita also described how ‘*mostly most of the work was done by the TA herself. I didn't see any like differentiate in work at all’*. Anne described how James’s school were not using colourful semantics even though he had been assessed as needing this to help him communicate, ‘*the feedback that comes back from the school is that they’re not doing it… because they're awaiting training’*. George questioned how children labelled with SEND and their parents are treated, suggesting that LAs and schools would not treat ‘typically developing’ children and their families in the same way.

As Ruitenberg (2011:28) describes, perhaps ‘the most influential ethical ideal in education has been the ideal of the autonomous, rational subject’, resulting in learning focusing on thinking ‘independently and rationally’ to become self-sufficient. Humanist ideas based on the Enlightenment ideas of what is means to be human pervade the education system, manifesting in policy, curriculum and pedagogy (Sidebottom, 2021). This results in the idea that pupils are acting independently within the education system as lone, autonomous and discrete units, rather than seeing them as ‘a student-in-composition-with a teacher and other students’ (Strom, 2017:107). It allows for a determination of who qualifies as meeting the ideal, and those who do not and can therefore be treated differently – whether this relates to the disabled child, or their mother. Accordingly, education can become an inhospitable and unwelcoming space.

However, when embracing an onto-epistemological shift towards a relational processual ontology that recognises the world as fluid and ‘constantly being co-created through ongoing material-discursive, nature-culture relations’ then it becomes necessary to recognise how ‘discourse, spaces, places and all other entities’ do not pre-exist, but ‘*emerge* as practices through relations in specific times and places among the various actors and perspectives that must coexist for students to learn in productive ways’ (Kayumova & Strom, 2023:unpaginated, original emphasis). This ontological shift enables a recognition of how both the pupil and the space are constantly becoming and emerging through relation and actions. As such, this shifts thinking from the notion of an isolated mother battling a hostile education system attempting to secure inclusion for their child in a pre-existing education space, to recognising mothers also as being constituted in relation, and acting within an assemblage that creates the event. As such, education settings cannot be assumed as a pre-existing ‘whole into which something (or someone) can be incorporated’ (Graham & Slee, 2008:278), rather it becomes necessary to recognise how the arrival of someone new ‘may change the space into which he or she is received’ (Ruitenberg, 2011:32). This is a shift from the idea of ‘inclusion’ which ‘implies a *bringing in’* to an ‘implicit centred-ness’ (Graham & Slee, 2008:278) to the opportunity for everyone in the space to have the opportunity to reimagine what it means to belong there.

During one conversation, Jayne discussed Zebedee’s sports day. She described how:

> *They had a bean bag race… it was a hot day, so they had sunhats on and they had to put beanbags on their head and then run. His kept falling off as did all the others. Yeah, he's like…. I've got a hat on. So, he took his hat off, put the bean bag on, put the hat back on and kept going. Like, I will do it my way thanks*.

She described another race:

> *there's a chair that they had to run around and then come back. He got as far as the chair just sat down, and I was kind of like, why not, there’s a chair*.

Garland-Thomson suggests that the experience of misfitting can be ‘generative rather than necessarily catastrophic for human beings’ as people learn to navigate their way through the world differently, as they gain skills or ‘innovative perspectives’ on adapting to challenging environments (Garland-Thomson, 2011:604). Taking part in sports day can be challenging for pupils who have Down syndrome, whether due to their understanding of the tasks, their short stature, poor balance and co-ordination, tiredness from hypermobility, or sensory overload. Zebedee’s body might not have been a neat ‘fit’ for competitive races, but he was able to find his own way to engage in the activities, changing the encounter to one that worked for him. The assemblage of the beanbag, the sunhat, the cheering crowds enabled Zebedee to produce something new, to make the sports day race more hospitable for him. He changed the rules of engagement in both races. The argument that I now go on to present is that not only do disabled children engage in activities, disability affordances, that can change the shape of the environment that they are in, but their mothers are doing so too.

Dokumaci (2023:61) describes how disabled people experience a ‘shrinking world of possibilities’ compared to others. Because of impairment of the body, there is a ‘limit to the environmental adjustments that can be made' to make the world more hospitable and accessible (Dokumaci, 2023:69). When it comes to the education of pupils who have Down syndrome, no matter how many adjustments or interventions are made, they will still have both cognitive and bodily impairments, as well as the social and cultural understandings and stereotypes relating to Down syndrome that I have previously discussed, which mean that they are likely to have a different engagement with the education system to their non-disabled peers. For them, the opportunities afforded by the education system are likely to be shrunk. What then becomes important, Dokumaci argues, is world-making acts which can transform 'the very definition of a liveable life' (Dokumaci, 2023:70), or in this instance it would be acts that transform our thinking on how different minds and bodies might fit within education. As Dokumaci (2023:53) points out, thinking with shrinkage allows a shift in focus from 'objects/subjects to processes', recognising that for many disabled people the removal of barriers cannot remedy an ableist and inhospitable habitus. Instead, there is a need for activist affordances which bring 'into being a new kinship imaginary' where there is room for impairment (Dokumaci, 2023:217). Mothers of disabled children already know that mainstream education settings are not set up for children who are cognitively disabled, so for their child to be meaningfully included, they know that they need to do more to make this happen.

In one conversation, Jayne discussed how, when Zebedee started school there was a parent's WhatsApp group:

> *I just sent a message to all the parents saying, erm you know, Zebedee has Down syndrome, just you know, just in case... So just sort of basically if your kids are kind of coming home with questions or whatever. Yeah, this is, he has Down syndrome. This is*

> *how it affects him'*.

She explained how she wanted the other parents to understand his differences to help them be welcoming of him. Sita described how she went on training and contacted the Down's Syndrome Association to get ideas how to support Kiran's development and behaviour before he started school. She described how '*nobody will tell you then how to get it right, you have to be proactive'*. Faith explained how she supported Brave's learning of vocabulary and spellings at home, '*I will make him big letters and I put for example that's the salt, the beans, the noodles'.* She described how the school were not recognising how much Brave could understand: '*nobody give me a solution. Okay, I'm going to make myself. I decide to do myself.* She also pondered on a life-changing moving back to South America which she felt would offer more inclusive education opportunities, because '*no, he's, he's not in good place in a good environment at the moment'*.

Clare discussed how, frustrated with the lack of speech therapy available locally, a group of mothers came together to:

> *challenge it en masse… there's the three of us who are sort of the guinea pigs here, that we're going to request tribunals. So we've supported each other with a WhatsApp document… so you know we're sort of sharing ideas*.

Instead of the tribunal being a solitary process, these mothers reimagined the process as a collaborative activity where they could work together to change the status quo for both their own and other children who have Down syndrome. In our conversations, several mothers discussed working with other parents to organise and provide speech therapy, early intervention groups or social activities for their children, to enable them to stand the best chance within education and their local communities. They also discussed paying for private assessments and therapies when these were not available from the LA. Clare described how the Down syndrome support group that she is a member of employs '*a private specialist teacher who comes into school, once every half term to support the school with ideas for, you know, how to differentiate learning, handwriting and maths, you know, things that work for him'.* She described the importance of arranging these interventions, as she did not want Thomas to be sad because he was '*failing on a daily basis'* or because he was '*being singled out and treated in a different way'*.

In Dokumaci's discussion of micro-activist affordances she describes how they are not and never have been 'one person's individual affair' (Dokumaci, 2020:98). She provides an example of a father in Istanbul carrying his son, Ahmet, in his arms every day, as it was the only way he could get to school due to the misfitting that took place between his chronic inflammation and the rough country terrain. This is an example of 'people as affordances', whereby Ahmet's father 'becomes an affordance for him' to enable him to access education (Dokumaci, 2020:98). The mothers in this inquiry could equally be seen as becoming affordances for their children. Whilst they might not be physically carrying their child to and from school to enable attendance, they are undertaking a range of activities to help minimise the misfitting between their child's impairment and the education system. Whether this is by teaching at home, going on training courses, collaborating over a tribunal appeal, or organising educational outreach, these mothers were not attempting to be warriors, rather they were wanting to make education more hospitable for their child, to reduce the shrinkage of the educational space.

These acts and performances, some of which might be seen as micro-acts, often go unnoticed as they take place outside of the formal meetings and documentation that surrounds pupils categorised as having SEND. However, they are all attempts at making changes for their child, to 'enable the emergence of affordances, or directly becoming affordances' (Dokumaci, 2023:207) to minimise the shrinkage of the education spaces that their children inhabit. As Dokumaci describes, 'when people create or directly become affordances for one another, they collectively dance and dwell in a more habitable and welcoming, accessible world in the very absence of those features that would make it so' (Dokumaci, 2023:209). Therefore, instead of suggesting that the pupil or the mother is to blame for not participating in the usually rationalist pattern of education, it becomes important to pay attention to the 'less formal, often unnoticed' spaces within which 'knowledge is produced and power is exchanged' (Price, 2011:60). Price (2011:61) describes these as 'kairotic' spaces, the spaces that sit outside of the formal education processes, but where there can be a relational 'real-time unfolding of events'. Mothers of disabled children can be seen to be pushing against the hostile and exclusionary 'materiality of institutional boundaries' to create such 'kairotic spaces', the 'lacunas without clear boundaries' (Dokumaci et al., 2023:368). Within these spaces, it is impossible to know in advance how others might respond (Glavan, 2020). The affordances made by mothers might manifest in a small one off moment that makes a particular event more hospitable, or they might have a longer term effect as habits form over time as they flex and bend the materiality of spaces.

Activist affordances performed by mothers of disabled children come into being because they have recognised the challenges that their children face when living in a shrunken world and engaging in an inhospitable education system. The affordances they make might not always remove barriers, but they are attempts to bring more ‘accessible futures’ into being through the ongoingness of their day-to-day activities, futures that maybe only they can imagine for their child and for themselves (Dokumaci et al., 2023:377). Their lives are likely to be full of such microactivist affordances, but this does not make them an activist or a warrior. Instead, they are engaging in processes that allow their disabled child to ‘dwell’ in a more habitable world (Dokumaci, 2020:100). They are in a process of becoming and world-making, where their actions ‘do not transform the world’ but are part of ‘the world transforming itself (Ingold, cited in Dokumaci, 2020:100). The love of a mother who believes in the value of education for their child might ‘misfit’ as she comes together with an education system that does not recognise their child’s value or humanity. As such they have no option, as Clare describes at the start of this part of the chapter, but to bring a new imaginary into being through their everyday actions, to remake and open up meaningful spaces through ‘intimate microactivist practices’ in their daily lives (Dokumaci, 2020:107).

This thread provides an alternative imaginary about the role of mothers of disabled children to emerge; rather than being warriors or lone individuals engaging in a battle against a hostile system, it is possible to see mothers as ‘becoming’ within hostile processes related to the education of their child. Instead of being paralysed by their engagement in the SEND system, their ongoing exhaustion can result in an affirmative and ‘personally situated advocacy’ whereby they are attempting to deal with the challenges and constraints that their child is facing (Glavan, 2020:345). This is a form of advocacy based on ‘intense devotion’; where the cost of ‘not advocating (that is, risk of harm to their child) appears much higher than the costs associated with the practice of advocacy itself' (Glavan, 2020:350). Faith describes how:

> *I feel like I am crossing a desert hoping to be heard and that one day, not too far away, we can receive the good news that our children are included in a society like any other person and can live a life of their own choosing what makes them happy. I believe that no parent deserves to go through this difficult and long process that seems to have no solution*.

Through their close enmeshed relationship with their disabled child, mothers will feel the pain and violence of their child's exclusion. Although at times there is complete exhaustion and personal sacrifice, the mothers in this inquiry advocate for their children in a range of ways daily. Many of these actions go unnoticed. However, through my use of Dokumaci's theory of affordances I have attempted to open a space for new conversations about the subjectivity of mothers of disabled children. When we shift from thinking about what the mothers do rather than attempting to think about who they are, we can see an unending commitment to securing a meaningful education for their child. Rather than categorising mothers, as seen in attempts by educators at the start of this chapter, it is necessary to pay attention to the mothers' performances which allow disability affordances to emerge.

10. THREAD – DOCUMATERIALITY

10.1 Introduction

Lucy Burke
@lucyburkeMcr

How many other families have boxes & boxes of paperwork to accompany every aspect of our children's lives? Just spent so much time on pointless form filling that sucks the air & light from our lives but, for some reason, I find it hard to throw it away: an archive of misery #SEND

11:14 AM · Nov 5, 2023 · **6,313** Views

Image 16: Tweet by Lucy Burke about piles of paperwork

'I can't show you my desk here, it is just full of SEN files' Emily

Since my daughter was born, I have been collecting paperwork. Piles of reports and documents, primarily documenting professionals' opinions of her disability, her physical growth, or her development and progress made since her very first days, gather dust in my filing cabinet. As Burke (2023) describes in the image above, this paperwork is 'hard to throw away' instead the boxes take up space in our home as an ever expanding 'archive of misery'. I used to judiciously file these in date order, carrying heavy folders to meetings, rarely opening them but the physical presence of the documents helping to add weight to any arguments I made. The weighty pile suggested that my arguments were rationally informed, based on either legal documents or professional advice. In recent years, as my daughter approaches adulthood, these files are now shared and stored digitally, housed in an ever expanding cloud-storage folder. Whilst these reports might carry the same emotional weight, they do not have the same physicality nor presence.

Parent/carer participants in a recent co-produced inquiry about carers' mental health, discussed how paperwork 'matters' and has 'meaning in their lives' (Runswick-Cole et al., under review). They described a 'fear' of not documenting something 'properly' or throwing away the documents as they never know if they might need to use them in the future as evidence to 'prove' the need for services and support (Runswick-Cole et al., under review). These files take up physical space in the home, yet as Runswick-Cole et al. describe, the role and materiality of this accumulated paperwork is rarely examined. This thread offers such an examination of both the materiality and the affect that documentation can have. I have termed this 'documateriality'.

Within the conversations that took place with mothers in this inquiry, the issue of paperwork, files and reports frequently arose. Anne and Faith both brought home-school communications books as their conversation starters, and Clare brought tribunal documentation to discuss. Clearly an engagement with documents, school reports, forms and piles of paperwork is an important aspect of being a mother of a disabled child. Indeed, within the conversations that took place, it was clear that the engagement with SEND-related documentation often falls to the mother. As Anne described *'It's like the EHCP, all the paperwork, I do all the paperwork'* and Clare alluded to similar with their family:

> *Usually, I'm the main one. Doing everything. So my husband really wouldn't be, I don't think he has a clue. If I were to send him to the meeting. No, he wouldn't. He wouldn't know what's going on.*

This higher-level of engagement by mothers is important to recognise, as this could mean that the materiality and affect of documentation will have a greater impact on them than on fathers who engage less with the SEND system.

The conversations with the mothers in this inquiry, in particular following Emily's comment above, set something in motion and I started to wonder about what the physical presence and materiality of documentation might 'do' in relation to parents of disabled children, and importantly what impact this might then have on their child's inclusion. Although documents can be presented as neutral and objective by professionals writing them, as Albin-Clark (2019:8) describes, documentation can be 'agential and performative'. When perceived this way, our focus turns to what documentation *does,* rather than simply what the documents say or how they are produced. Prior (2003:91) suggests that documents are 'never inert' but play a role through which subjectivity is both 'created and stabilized'. Reports and other documents are therefore not just 'tools to be used' but individuals, worlds and futures can be 'constituted in and through documentation' (Prior, 2003:167).

Prior (2003:2) reminds us that the status of documents 'depends not so much on features intrinsic to their existence, nor even on the intentions of their makers, but on factors and processes that lay beyond their boundaries'. It is important therefore to consider how documents 'function' or what 'documents do' (Kummen, 2014:821). It is also necessary to recognise how 'documentation is done in certain places and at certain times' and the various factors that are 'entangled in the documentation process' (Pettersson, 2019:197), meaning that the context within which it a document is produced or stored is also important to consider. Whilst I recognise that documents themselves can be seen as 'insightful and rich data sources' (Barlow, 2015:378), my intention here is not to interrogate the documents and what they say nor to discuss maternal engagement in the EHCP process, as others have done (eg. Keville et al., 2024). Instead, I consider how documents come to 'matter' and what realities are produced through documentation processes and performances (Kummen, 2014; Pettersson, 2017).

10.2 Documentation practices within the SEND system

Practices of examination and documentation have long been used in relation to the education of disabled children. In the 1800s ‘imbeciles’ and ‘feeble-minded’ children were separated out from ‘ordinary children’ to either attend residential training or ‘special’ instruction (Tomlinson, 1981:35). The first special schools opened in London in the late 19th century, and pupils were admitted following observation and an examination by medical professionals and school inspectors (Tomlinson, 1981). In the early 20th century, increasing numbers of ‘defective’ children were identified (Tomlinson, 1981:37), who could not be taught in ordinary schools, though there was concern about identifying too many pupils as disabled, because disability was ‘an expensive problem to deal with’ (Humphries & Gordon, 1992:57). This was the start of processes that involve assessment, identification of ‘deficit’ and documentation that evidences this and is used to decide which type of education for a disabled pupil is most suitable. This has always primarily been a professional-led process, though from the 1970s the Government recommended that parents should be involved in the decision-making process and their views should be sought. There has been a growing emphasis on parental engagement and participation since the 1978 *Warnock Report* introduced the notion of ‘Parents as Partners’ along with a recommendation that parents are given ‘a form on which to make their own statement about their child's needs’ during statutory assessments (DES, 1978:67).

Today, assessment and documentation practices for disabled children in the English policy context centre primarily around the EHCP both in terms of an initial assessment and then the ongoing Annual Review process. EHCPs were introduced in the 2014 SEND reforms. An EHCP is a statutory document that is issued to children and young people (0-25yrs) who are assessed as having SEND that cannot be met within a mainstream education setting without additional provision. Pupils labelled as having SEND whose needs can be met in a mainstream setting without additional provision set out in an EHCP should have their needs met by an 'Assess-plan-do-review' graduated response within a new category of 'SEN Support'[69]. It is therefore only pupils who have an EHCP who can access specialist education settings.

To secure an EHCP for a child or young person, there is a 20-week statutory assessment process. Parents can request an EHC needs assessment, as can anyone else who thinks such an assessment may be necessary (DfE & DHSC, 2015). The LA has to determine whether a child/young person may have SEN that may need an EHCP, based on the evidence provided, and if so they must undertake an EHC needs assessment. As part of the EHC needs assessment, local authorities will seek evidence of needs, including the 'views, interests and aspirations of the parents' (DfE & DHSC, 2015:142). If the LA decide to issue an EHCP, they must send a draft plan to parents, who have the right to 'provide views' on the draft and request a particular school be named (DfE & DHSC, 2015:152,171). Although, as Satherley & Norwich (2022:961) explain, there is a narrative of parental school choice, most parents of

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[69] SEN Support is the category where a pupil received extra or different help from that provided as part of the school's usual curriculum. See https://www.gov.uk/children-with-special-educational-needs/special-educational-needs-support for examples of the type of support.

children labelled with SEND ‘did not believe that they had a “real choice” of schools because there was a lack of options relevant to their child’s needs’. As Cologon (2022:410) describes, it is merely an ‘illusion of “choice”’ for those whose children are not constructed as ‘other’ to the typically developing child, for whom inclusion can be presumed. Mainstream schools will often say that they cannot ‘meet needs’ of pupils labelled as having SEND, however there are also not enough spaces in specialist provision for pupils whose parents seek places there (Martin, 2023). As a result, thousands of children often must travel more than 20 miles to attend school (Davies, 2022) or their parents will ‘seek refuge through home schooling’ (Slee, 2019:916). After parents have provided their input, the authority will issue a final legally-binding plan together with copies of all evidence obtained, which is implemented and then reviewed through a formal Annual Review process, where all parties submit updated evidence so that the LA can decide whether to maintain, amend or cease the EHCP. At various stages in the EHCP assessment process and after each Annual Review, young people and parents have the right to appeal against the LA decision to the SENDIST Upper Tier Tribunal (DfE & DHSC, 2015).

As previously mentioned in Chapter Five, a pervasive narrative exists that suggests that parents see an EHCP as a ‘golden ticket’ to access support for their child. For example, St Paul Chambers described ‘a ‘golden ticket’ mentality surrounding EHCP’ (St Paul Chambers, 2015) and the Education Select Committee reported in 2020 that ‘[r]eceipt of these EHC plans has become a ‘golden ticket’ that parents fight for to try and secure access to adequate support for their children’ (Education Committee, 2020). This phrasing is often attributed to parents, suggesting that parents are the ones talking about ‘golden tickets.’ However, as I have discussed elsewhere (Smith, 2023), this can only be traced to one parent using this language, following which it is other stakeholders who have continued to perpetuate this positioning of the EHCP, whilst supporting a pervasive parent blame agenda.

Image 17: A golden ticket created at an 'Embroidery & Resistance' workshop at LSE

10.3 A 'hostile' SEND system.

Research that specifically discusses paperwork and documentation is often approached from the teacher or SENCO perspective, for instance highlighting how teachers face pressures from 'a relentless requirement for the completion of paperwork' (Male & May, 1997:138), how SENCOs often experience frustration with the demands of paperwork (Mackenzie, 2012) or how professionals find the EHCP process 'to be a burden, with time-consuming paperwork' (Ahad et al., 2022:16). Palikara et al. (2019:89) describe how the 2014 SEND reforms led to an increase in bureaucracy for SENCOs, who are subsequently 'drowning in paperwork' due to taking on additional administrative responsibilities[70]. Richards (2022) further discusses the challenges SENCOs face with getting reports or summaries from other professionals, and the challenges of multi-agency working, as well as the range in quality and usefulness of documents produced. This focus on professionals' experiences of documentation, rather than parents' perspectives, is not a surprise given that the overall responsibility for producing and implementing most of the documentation, eg. progress reports or the EHCP, sits with professionals, who are also ultimately responsible for developing effective parental engagement (Broomhead, 2018).

Research undertaken with parents tends to focus on associated EHCP assessment processes, rather than explicit discussions about their engagement or experiences of paperwork. For instance Kendall (2019) discusses the difficulties parents of children who have Down syndrome face during the EHCP assessment process, where there is a lack of discussion between parents and other agencies, and poor communication. Parents also state feeling unsupported during the assessment process (Dunleavy & Sorte, 2022), dissatisfaction with inconsistent application of the Code of Practice guidance[71], which results in EHCPs that do not adequately quantify the provision their child is entitled to (Sales & Vincent, 2018; Starkie, 2023) or are of variable quality (Cochrane & Soni, 2020), and frustration that the provision contained within an EHCP that their child is legally entitled to is subsequently not provided

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[70] Interestingly, as I discuss in Chapter Ten, parents also describe themselves as drowning in paperwork when discussing their experiences.

[71] It should, of course, be noted that the SEND Code of Practice has what Allan & Youdell (2017) describe as an 'empty architecture' which can lead to different expectations (Allan & Youdell, 2017:72-3).

(Bentley, 2017). All of these previous findings in research were also evident within the conversations that took place within this inquiry. The numerous challenges parents face when engaging in the EHCP process are well-documented in academic research and have also been recognised within the government's SEND Review and the current *SEND & Alternative Provision Improvement Plan* (HM Government, 2023). It is therefore not surprising that within the conversations in this inquiry, similar frustrations were aired. For example Anne described being '*deep in the middle of an EHCP hole*' in relation to securing her son James's speech and language provision, whereas Jayne described how she faced a battle getting enough support for her son Zebedee in his EHCP '*so that he has half a chance coping in a mainstream school'*. Mothers understand that their ongoing engagement in the EHCP process is key to secure the provision their child needs to succeed in education, however difficult the experience is.

As Bentley (2017:134) describes, parents can find 'the EHC needs assessment process as highly emotional, stressful and anxiety-provoking', a sentiment that was also echoed in the conversations that took place within this inquiry. Clare described the EHCP process as '*a hostile environment'*, explaining how it took her '*months and months to get a draft and final plan'*, where the ongoing failure to issue the plan prevented her from appealing the contents of the EHCP, and George described her frustration and ongoing stress because the LA failed to issue Ezra's final EHCP naming his secondary school by the statutory SEND school placement deadline. She described how she was left unable to buy school uniform, apply for transport or prepare Ezra for his transition to a new school. Again, these conversations echo and support other research, for example the everyday failings that children labelled with

SEND face and the levels of stress and anxiety that is experienced by parents as a result (Dunleavy & Sorte, 2022).

The usefulness of EHCPs was also questioned in our conversations, as questions were raised as to whether they help at all once in place. For example Emily discussed how Ethan's EHCP was incredibly detailed, but '*nobody's clearly read it'*, whilst also describing its limitations as a meaningful document for those educating him, given that it doesn't mention how '*Ethan hates snow*' and that '*he won't wear a hat'.* Sita described how Kiran's EHCP was never updated after any annual review meetings, even though this is what she thought the meetings were for, whilst Faith discussed how Brave's school simply '*don't apply what is in his EHCP'.* Whilst LAs produce the EHCP following the assessment process, it is primarily left to schools to deliver most of the provision within the plan, who are reported to feeling left to themselves to do this, 'without the training and support of the services who had identified the provision' (Cochrane & Soni, 2020:384).

Engaging with education, health and care professionals clearly presents a range of challenges for mothers of disabled children who are seeking support for their child, and even the most informed and educated parents still find this difficult (Long, 2023). Parents frequently experience the 'SEND system as complicated and difficult to navigate, requiring a high level of active involvement' (Hellawell, 2019:102). The conversations that took place with the mothers in this inquiry again support these earlier research findings, as well as the need for urgent SEND reform. However, as I will now go on to discuss there are other ways to consider the role that SEND documentation plays which previous research has not yet considered, for example the material affects it produces and the impact this can have on the decisions that mothers make about their child’s future education.

10.4 Approaching documentation differently

I now move on to consider the ‘force and power’ that documentation might have to ‘transform our thinking and being in a particular space or in the world at large’ (Lenz Taguchi, 2010:4). As Lenz Taguchi (2010) describes, ‘notions and beliefs can change as a result of the force of intra-activity with material objects and artefacts**’** (Lenz Taguchi, 2010:5). Within this thread I will now explore how documents create ‘conditions of possibility’ (Ferraris, 2013:320), as the materiality and agentic nature of documents, which I have termed ‘documateriality’, shapes what mothers of disabled children think is possible or desirable in relation to their child’s inclusion in education.

The documents related to SEN processes are what Ferraris (2013:43) calls ‘social objects’, which are ‘dependent on subjects’. Documentation fixes social acts that have involved at least two people into a stable object as they are ‘inscribed’ onto a ‘physical medium’ (Ferraris, 2013:159). This physical medium gives the inscribed social act a permanency, ensuring that it endures over time (Ferraris, 2013). Documents therefore inscribe acts, fix them, make them portable and ‘available beyond the here-and-now that generated them’ (Ferraris, 2013:270). Ferraris (2013:271) draws on the term ‘documentality’ to describe how ‘paperwork is indispensable to live and to have power’. He describes how documents can inscribe rights to individuals, giving increased control, but equally, when part of complex bureaucratic executions, they can foster the illusion of power whilst resulting in a growth in institutional control (Ferraris, 2013:271). I am introducing the term ‘documateriality’ to instead draw attention to the agentic power and affect that the materiality of documentation can have, which I go on to describe in this thread.

Despite an extensive search, I have been able to find very few researchers engaging with SEND documentation as an ‘active performative agent’ (Lenz Taguchi, 2010:22). One noticeable exception to this is a discussion from a teacher’s perspective, where Hohti (2018) discusses her engagement with documentation as a material object and its affects in relation to an individual pupil, Siiri. As I discuss further below, she describes how a tick on a form ‘was powerful and agentic enough to bring something to exist and to ignore other things’ (Hohti, 2018:12-13). This resulted in the documentation telling one story about Siiri, to the exclusion of ‘the glowing and sizzling of a thousand stories of differentiation’ that might otherwise be told (Hohti, 2018:15). Most of the existing scholarship engaging theoretically with documentation as agential matter that I have found relates to early childhood education, with little or no discussion of SEN or disability (Lenz Taguchi, 2010; Murris, 2016; Pettersson, 2019; Albin-Clark, 2021). To explore documateriality I will draw on this body of work alongside the conversations that took place with the mothers in this inquiry to think differently about SEND documentation.

10.5 An agentic reading of documentation

> A colleague came to the teachers' room, where I was sitting with the form, and said, "Yes, concerning Siiri, I recognise what you are talking about: Definitely, in my lessons, she has these kinds of difficulties, too. You know, she'll never get any help unless you tick a strong statement. There simply are no resources; the healthcare professionals will not react to anything mild." (Hohti, 2018:12).

Practices of documentation 'can be thought of as apparatuses that produce, rather than represent, a reality' (Pettersson, 2019:195). They are 'boundary-making practices' (Pettersson, 2019:196), through which various entities, including both pupils who are labelled as 'having SEND' and their parents, are produced. Pettersson (2019:203) describes how 'past, present and future are enfolded, entangled, produce and are produced' through documentation practices. Documentation 'is part of the fabric and practice' of schools (Albin-Clark, 2019:135), and this is particularly the case for children who are considered to have SEND. For these pupils, documentation records assessments of progress and individual 'need' and makes recommendations about what provision will be made and what outcomes are being sought in the future. Rather than being passive, documents are performative apparatuses that enact 'what matters and what is excluded from mattering' (Barad, 2007:148). Both knowledges and realities are therefore produced in documentation practices. Documentation maps the '*effects'* of difference (Murris, 2016:39, original emphasis). It becomes necessary, therefore, to engage in 'agentic readings of documentation practices' (Albin-Clark, 2021:141) when thinking about how inclusion and exclusions might be produced for disabled pupils.

When documentation is recognised as 'agentic', forms, templates, worksheets - or as seen in this inquiry EHCPs – can take on a new force as they 'participate actively' in shaping educational practices (Pettersson, 2019:196). They can determine which knowledges matter and what entities are produced. As Pettersson (2017:6) describes, 'things such as models, templates, and national guidelines are all performative'. Templates determine 'what is possible to document' and 'what is made important enough to document' (Pettersson, 2017:6). Although, as discussed above, parents now have greater input in EHCP-related processes than previously, the professional voice remains a dominant one. Parents are invited to submit their views as part of the EHCP assessment and Annual Review processes, often in the form of an 'Our Story' or 'All about us' booklet, with set questions and sometimes even specified wordcounts per field. Whereas professionals will submit a formal report documenting their expert opinion underscored by a signature. These professional reports document observations made by an objective and passive observer, an individual who is qualified to make a judgement. The observations will be used to measure a pupil's development in comparison to other children and are considered 'a truth' (Lenz Taguchi, 2010:72) that can objectively be relied on.

Following submission of the documentation to the LA, parental views and those of the child/young person tend to be summarised by the LA and included in Section A of the EHCP, whereas it is the professionals' views that determine what assessed 'needs' and specified 'provision' are included in the subsequent sections of the plan. There is therefore a difference in the weight given to parent's views vs professional reports. Faith described asking the speech therapist to discuss specific topics to ensure that her concerns could be heard, because '*if the professional say [it], the school going to value it'.* Greater weight is also given to reports commissioned by local authorities, rather than those resulting from professional assessments that parents have paid for or parental opinion. As Clare described, '*they commissioned an expert report and I commissioned an expert report, then they ignored my expert report, said we don't do things like that in this area'.* Emily described submitting a report at an Annual Review meeting following an extensive period of homeschooling Ethan post-Covid, but despite the detail in the report and her own professional qualifications, '*the school dismissed that, SEN dismissed that, and they refused to put it in the EHCP'*[72]. The school's knowledge of Ethan was deemed more credible than Emily's even though he had not been in school and was being educated at home by a tutor. Hierarchies of which knowledges matter exist (Hodge & Runswick-Cole, 2008), and these become materialised within EHCP documentation processes.

As a result of these hierarchies of knowledge, some mothers see it as necessary to develop 'a level of professional knowledge' by going on training courses and gaining new skills (Hodge & Runswick-Cole, 2008:640). As Clare described, '*I wouldn't ever begrudge the time that I spend on this and, you know, it's become my specialist subject, if I was going on Mastermind you know I would absolutely ace it'.* However, despite this knowledge many mothers gain, their contributions are often reduced to feelings (Pluquailec & O'Connor, 2023) and are therefore disregarded. Indeed, as previously described, mothers of disabled children are often deemed to be mad or irrational (Runswick-Cole et al., 2024), which enables their contributions to be ignored.

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[72] 'SEN' is sometimes used by mothers as a shortening of 'SEN Team' within the local authority.

Hohti describes how their memories relating to Siiri and 'practices, beings, and differences' became constituted through relations and paperwork. Siiri's mother emailed about a form Hohti had filled in, asking for an explanation as to why a particular box had been ticked. The form offered five alternative answers about whether Siiri might say socially inappropriate things. Hohti (2018:10-11) describes having 'real difficulty deciding which alternative to tick' as she sat and thought about Siiri and her behaviour in class. Unsure which box to tick, Hohti visited previous professional reports and discovered an unwillingness to answer questions documented when in preschool, following which she ticked the 'occurs often' box. This action of ticking the box 'created a confident voice' for her as teacher, and the tick 'was powerful and agentic enough to bring something to exist and to ignore other things'; the choice of where to place the tick made her 'tell one story instead of a thousand other stories' (Hohti, 2018:12-3). Siiri became constituted as having abnormal behaviour, in need of special support. Documentation practices such as this can either challenge or reinforce teachers' pre-conceptions about children in their classroom. They can also ascertain who does or doesn't belong in a particular setting (Albin-Clark, 2019)[73].

Observation and documentation has historically been and continues to be used extensively in education, to identify 'deficiencies' and the need for 'intervention' in education, based on knowledge from developmental psychology (Lenz Taguchi, 2010:7). Documenting a child's 'special educational needs' results in them being constituted in a particular way, to the exclusion of other ways of thinking about the child. The documentation gives educational needs a 'material form' (Barad, 2007:91) and shapes responses to the child who now

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[73] I discuss belonging further in Chapter Eleven.

materially ‘has’ SEND. As Murris (2016:157) describes, it is important to consider ‘the configurations of child that have been brought into existence through the materialdiscursive practices’ of documentation. Children’s development and achievements are increasingly documented within ‘institutional monitoring and interventional processes across education, health and social care sectors’ (Albin-Clark, 2019:35). Disabled children and their parents experience greater levels of monitoring and a high level of interactions with professionals when compared to other families (Ryan & Runswick-Cole, 2009), therefore the impact of ‘documateriality’ will be greater on pupils who are labelled with SEND and their families.

In a recent analysis of the 2022 SEND Review Green Paper, Pluquailec & O’Connor (2023:11) describe a worrying shift in discourse where pupils ‘are no longer described as ‘needing’ something from others: they simply “have sen/d”’. They argue that this discourse sees pupils ‘construed as passive bearers of disability’, where their ‘needs’ are characterised as ‘obstacles to “the system”’ (Pluquailec & O’Connor, 2023:11). As Clare described, ‘*it’s really easy to sort of dehumanise our children when they are just words on a paper’*. Discourses become ‘intertwined and intra-acting with the agency of all other bodies, materials and artefacts in the world, with no clear-cut boundaries between them’ (Lenz Taguchi, 2010:24). As such, the shift in discourse will intra-act with national policy documents, as discussed by Pluquailec & O’Connor, and also with practices in education settings, ‘ AND… AND… AND…’ (Deleuze & Parnet, 1977:10).

The EHCP document is complex, consisting of several mandatory sections which set out needs, provision, and outcomes. The document also determines responsibility for funding and providing the provision. Individual contributions and reports will shape its development and 'can affect how the plan is crafted' and what future outcomes are desired (Long, 2023:154). However, not all parents understand the different sections of the plan, or the need to have specific recommendations within the enforceable sections (Long, 2023). As Jayne described, it was only when a Headteacher looked at Zebedee's EHCP and told her how '*terrible*' it was, that she realised '*there was literally no support in his EHCP. It was the most vague, I didn't realise'*. When she spoke to other mothers in a support group, she also came to realise that '*EHCPs are often a nightmare*' following which she recognised the need to take the EHCP process seriously.

It is also important to consider the relations, including those with parents, that 'make the documentation possible' (Murris, 2016:157). As mentioned previously, when mothers of disabled children complete EHCP paperwork they are expected to describe their children in terms of their deficits and the challenges that they are facing. Knowledge is created and materialised through the completion of these forms, which go on to form part of the formal documentation records for their child to be referred to in the future. Of course, mothers not only have to complete documentation highlighting their child's 'deficits' to secure education support, but also for benefits applications, requests for respite/social care input and to obtain things as everyday as access passes to use at the theatre or theme park. Therefore, through necessity, they are engaged in documentation practices that construct their child as 'other' as a child who 'has SEND' and who needs additional resources to be able to educated within a mainstream setting, or who requires separate specialist education. There are prescribed ways of engaging, which mothers must learn to navigate to secure a meaningful education. Within these processes there is little, if any, room for including alternative knowledges about their child, eg. any suggestion of discussing strengths or admired qualities. For mothers to secure the support that their child needs to be included in education, there is only one way to complete these forms, and this is by focussing on the things that their child cannot do. This can be a particularly stressful and difficult experience and it can have impacts on parent and family wellbeing (Long, 2023). Jayne described how before Zebedee even started school she was '*slightly traumatised by the EHCP'.*

Having an EHCP immediately signifies that a child requires additional support and resources over and above those normally available in a mainstream setting. Immediately the bearer of an EHCP is constituted as a child that is 'other', as outside of what is considered normal within a mainstream environment. The EHCP assessment process involves a requirement for the LA to 'consult' with potential schools, sending them a copy of the documentation following which they must 'consider their comments very carefully before deciding whether to name it in the child or young person's EHC plan' (DfE & DHSC, 2015:172). Parents can name their preferred setting, which must be consulted, but the final decision sits with the LA about which school to name. Jayne reported that schools were resisting her visiting them when she was looking for a school for Zebedee. She described

> *because a lot of the schools were already full up or had no capacity or they already had children with EHCPs already. They were like, Ahhhh, another child with a EHCP*.

Here the EHCP can be seen as a performative agent of exclusion (Lenz Taguchi, 2010), as schools turn away children who have EHCPs, yet cannot choose the characteristics of other members of the school population.

Once the EHCP is in place and a school placement is agreed, the document shapes what education provision and support should be made available to the pupil and who is responsible for delivering this. As Sita described, everything '*has to be written in the EHCP, if it's not, then they're not gonna do it'*. This demonstrates the importance parents place on the provision needed being detailed and specific within the EHCP document. Emily described how '*There is quite lot of detail in Ethan's EHCP that I put in, which should raise a few eyebrows and ask questions'* and Jayne described how she secured SALT provision in Zebedee's EHCP:

> *I actually cut and pasted, everything I wanted in the EHCP right from my speech language report. And I emailed them said, I know you're really busy. I just wanted to try and make this really easy for you. Here it is, can you just cut and paste this, put it in the EHCP. Thank you very much. And they did*.

However, as Faith described, schools do not always follow what is in the EHCP. Despite Brave having speech therapy written into his EHCP, this was not being delivered. She described how '*they don't apply what is in his EHCP'* and Anne raised similar concerns, asking:

> *is he doing what he needs to be doing in terms of what's in his EHCP. I'm not sure, I'm not sure that he's actually getting the stuff that is, is, outlined in his EHCP so what's the point?*

George described her frustrations at documented provision not being made available for Ezra, stating that her '*favourite sentence'* to use with his school is '*It is in his EHCP'*. Once obtained, the EHCP document can also become a powerful tool for parents to use to both secure and demand the provision their child is legally entitled to, but this often requires lengthy, expensive and adversarial dispute resolution processes to be followed.

Despite the formal processes that state when the EHCP can be amended, George, Anne and Clare all described how their LA had changed their sons' EHCPs '*by stealth'* (Clare) without either their agreement or evidence to back up their decisions. As George described, her LA changed the funding associated with the EHCP which held up Ezra's transition to secondary school, yet '*there isn't even a reason as to why they did it'*. Clare, generously, pondered whether the removal of Thomas's Speech & Language Therapy (SALT) provision was '*an error'*.

Furthermore, professionals do not always engage fully in the process, for instance Clare described how '*SEN Case officers do not attend EHCP reviews'*, Faith described how when Brave's annual review took place there was '*no report from the school'* or the speech and language therapist, and Anne similarly described how '*The SaLT*[74] *hadn't produced a report'* for James's annual review either. The professionals engaged in documentation processes miss deadlines, fail to respond to requests for information, and do not always submit the required paperwork. Clare described how the LA '*deliberately withhold information and make the process as confusing and as opaque as they can'.* These examples demonstrate how power is enacted when professionals withhold documentation, as well as the agentic capacity of documentation that is produced and relied on as evidence of need. Without the reports from school or therapists, parents become unable to fully engage in the processes to secure their child's education support and will often have to chase for reports or escalate complaints. As Runswick-Cole et al. (2024:in print) describe, mothers are accordingly

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[74] Speech and Language Therapist

produced ‘as unreasonable, demanding, and their opinions are dismissed to the point where they begin to doubt themselves’.

The EHCP process is an individualised exercise, focussed on one pupil. And yet, within the conversations that took place, it became clear that mothers do not always engage with documentation processes in isolation. As mentioned previously, Jayne secured advice about EHCPs from parent support groups, whereas Anne described how they:

> *got a couple of James's friends from his class to call and had pizza with us to talk about the EHCP and we're all sat around… you know, saying so what do you think… we just kind of literally went through the EHCP… from his perspective, because… there was kind of part of me thinking, how that how the hell am I supposed to be filling it*.

Clare described how she feels parents are ‘*stronger together’* rather than acting *‘in silos’* on our own. She and two other mothers ‘*who are sort of the guinea pigs here’* decided to challenge the LA's blanket policy about speech therapy for children who have Down syndrome. Recognising how difficult it is to challenge such policies en masse, they all submitted a SENDIST tribunal appeal simultaneously. They collaborated using a WhatsApp group and a shared document, as they gathered evidence and produced their tribunal paperwork. Clare brought this paperwork as her conversation starter. She described how ‘*we've shared the same articles’* and ‘*one of our parents is also a speech therapist. I think she'd flagged a couple of things*’. As Braidotti (in Dernikos et al., 2020:49) described, it is necessary to:

> Function in a group, function in a pack, make an assemblage. Function in a herd. Run with the she-wolves. Do not imagine for a minute that you can take on this system alone.

Instead of engaging in documentation practices in the individualised way they are intended, these mothers use documentation in collaboration with others. As Lenz Taguchi (2010:28) describes, '[i]f practice is produced and emerges through all of us collectively thinking, talking and doing it into existence, we might also be able to collectively re-think, re-talk and re-do practice differently'. The actions of Clare and the other mothers she is collaborating with can be recognised as an event that produces difference in a system that focuses on individual engagement and 'needs'[75]. The potentiality for 'becoming-other' exists within 'actions, interactions and events' and their affects (Fox & Alldred, 2017:179). The co-produced tribunal report that each mother submits simultaneously potentially sets something new in motion, a line of flight, creating new ways of meaning-making and new forms of relations with documentation.

10.6 Documenting solidarity and resistance through humour and creativity

In one of our conversations, Clare described how '*when you have a child with additional needs you get quite sort of dark sense of humour and you have this sort of erm, you know, you kind of find things funny that other people don't find funny'*. Any visit to the spaces on social media that are frequented by parents of disabled children will uncover conversations and 'in-jokes' about parents' experiences of the SEND system. I now move on to a discussion of memes, which are frequently used by mothers of disabled children as public acts of resistance on social media platforms.

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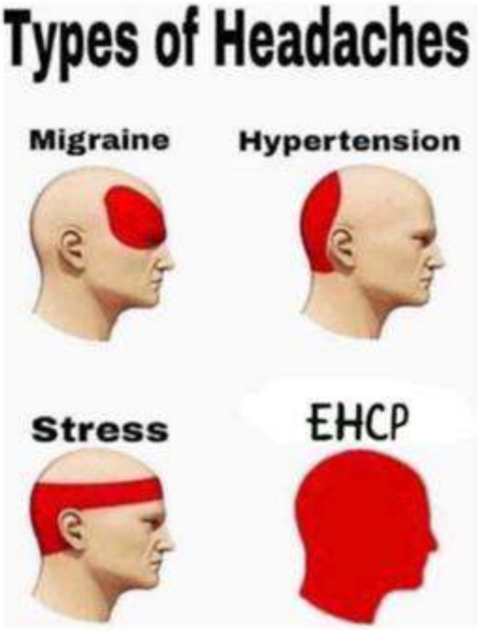
[75] This could also be seen as an activist affordance, as discussed in the previous chapter.


NEVER be afraid to challenge a comment, a report, an opinion...
...professionals don't always get it right!
@nomagicwanduk.com


What Dealing With EHCPs Feels Like ...
Are they even going to fund this?
Still here!
Unlawful stuff in the draft
More waiting
More paperwork
Waiting
SALT
Tier 1 Tribunal
Refusal to Assess
Mediation cert
Settling
Paperwork
© The Long Road 2022


Types of Headaches
Migraine
Hypertension
Stress
EHCP


EHCP's Must have ALL SEND needs included, and provision for Every need.
EHCP's are NOT a pic'n'mix.


ON RECEIVING DRAFTS 1, 2 AND 3
OF YOUR CHILD'S EHCP.


STILL WAITING FOR THE EHCP...

EHCPs, reports and paperwork are popular themes within memes produced and shared by mothers of disabled children, where words and images are combined to draw attention to several aspects of the SEND process, such as the wait for the draft EHCP document, the multiple inadequate versions that are rejected, the stress of the process and the sheer weight of the documents that are piling up. Although these memes are ‘generated for fun’, to use humour to share real life experiences in solidarity with others, they also are significant in the political points that they are making and their contribution to public discourses (Badenhorst & Guerin, 2016:9).

Memes are ‘widely replicated “texts”’ that aim to grab attention through the messages they convey (Badenhorst & Guerin, 2016:5-6). They are therefore public and spreadable by nature. Importantly, memes ‘“speak” to affinity groups’, and are frequently shared in spaces where people are gathering because of mutual interests (Badenhorst & Guerin, 2016:9). As Badenhorst & Guerin (2016:7) describe, memes are not isolated images but can indicate a ‘collective story’ as they ‘evolve and morph along a particular theme’. They can therefore contribute to a ‘collective identity’, through their ongoing production and performance (Gal et al., 2016:1699). Memes offer a way for groups to negotiate norms and power structures, or to subvert norms through a ‘performative act’ (Gal et al., 2016:1700). Memes shape language and thought and ‘possess *virtual physicality’* (Wiggins & Bowers, 2015:1891, original emphasis). Therefore, although they primarily only exist in the virtual world, they still possess material properties and can be seen to have agentic capacities.

In 2022, the Disabled Children's Partnership ran a social media campaign #SENDABetterMessage where they asked parents to share photos that would demonstrate the injustices within the SEND system. These were collated into an online exhibition, which included several images relating to documentation, eg. one showing the visible difference in paperwork for disabled children in comparison to non-disabled children, a mother 'drowning in paperwork' and a 'tower of paperwork' almost as tall as the mother stood alongside (Disabled Children's Partnership, 2022).

The online exhibition also featured an art installation from mother/carer Kerry Fox, who constructed 'Ode to Bureaucracy' out of EHCPs using the materials to highlight the challenges parents face navigating the SEND system as a form of art activism (Disabled Children's Partnership, 2022). She described how art provides 'an avenue to have a voice other than through the usual channels' and that to complain 'through art is much more enjoyable than the usual moaning letter' (York St. John University, 2019). Fox has continued to make art installations highlighting the challenges faced by parents, for example *The Mother Chair*, which asks how many forms and appeals a carer made today (Fox, 2023).

Image 18: Ode to Bureaucracy (Fox, 2021)[76]

Image 19: The Mother Chair (Fox, 2023)[77]

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[76] Reproduced with written permission from Kerry Fox (artist)
[77] Reproduced with written permission from Kerry Fox (artist)

Fox & Alldred (2017:78-9) describe how creativity is ‘inextricably a material process’ within a shifting network of human and non-human entities. There is ‘a fluid and fluctuating maelstrom of interacting bodies and things, ideas and social formations’ and ‘an endless cascading stream of events’ that produces the world as ‘constantly becoming’ (Fox & Alldred, 2017:77). Some of this production is ‘social’, where an ‘interaction, an emotion, a word, thought or idea, a new association or collectivity’ might lead us in new directions (Fox & Alldred, 2017:77). The memes and submissions to the online gallery set up by the Disabled Children’s Partnership drew attention to the challenges of documentation, to raise awareness and to incite positive action. However, what is important here is not what these creative material productions say, but what they do, what they might set in motion.

Memes can go beyond their initial aims of offering mutual support and shared jokes within a community, due to their agentic capacities and the affective flows that are produced within ever-changing assemblages. The ‘performative consequences’ of memes can be both ‘meaning-making’ and can play a role in boundary making (Gal et al., 2016:1699) and identity formation. When you collate memes created by parents of disabled children about a particular topic, it becomes possible to see the ‘aggregating affects’ (Fox & Alldred, 2017:85) which can create ‘converging identities or capacities’ (Fox & Alldred, 2017:32). The sharing of memes as a ‘performative act’ might contribute to a sense of belonging[78] within a community, this can also act as public ‘boundary work’ which constructs both individuals and collectives (Gal et al,. 2016:1700-1). As such ‘creative-assemblages’ will ‘have an existence, a life even, independent of human bodies’ due to their capacity to affect as non-human

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[78] I discuss belonging further in Chapter Eleven.

materialities (Fox & Alldred, 2017:85).

The creation of memes is a practice of meaning-making, one that materialises many of the frustrations felt by parents who are engaging in the SEND system. It is therefore important to recognise how the aggregating affects, as described by Fox & Alldred (2017:85) can lead to more 'stable forms' and identities. Whilst material creative productions can create '"nomadic" spaces of possibilities for action or desire' (Fox & Alldred, 2017:85), they can also, through aggregating affects, be reproducing established forms of relation and discourses about parents of disabled children, for instance as confrontational or demanding. The use of memes can further entrench identify positions, which potentially has the opposite effect to those originally intended. This is because, as Fox & Alldred (2017:79) claim, creativity is not just an 'individualized human "spark", but it is always located within a broader network of bodies, things and ideas' (Fox & Alldred, 2017:79).

Albin-Clark (2021:151) discusses how documentation 'operates within a policy landscape with complex sets of drivers at work'. It is important to consider how parental public acts of resistance are 'processual and transitory' and do not stand outside of 'material affectivity' (Fox & Alldred, 2017:27). Whilst on first glance, memes can appear to be supportive and fun, or an act of resistance, further inquiry would be useful to understand how memetic acts might fix mothers of disabled children within particular identity categories and also how they might shape what it means in relation to belonging[79].

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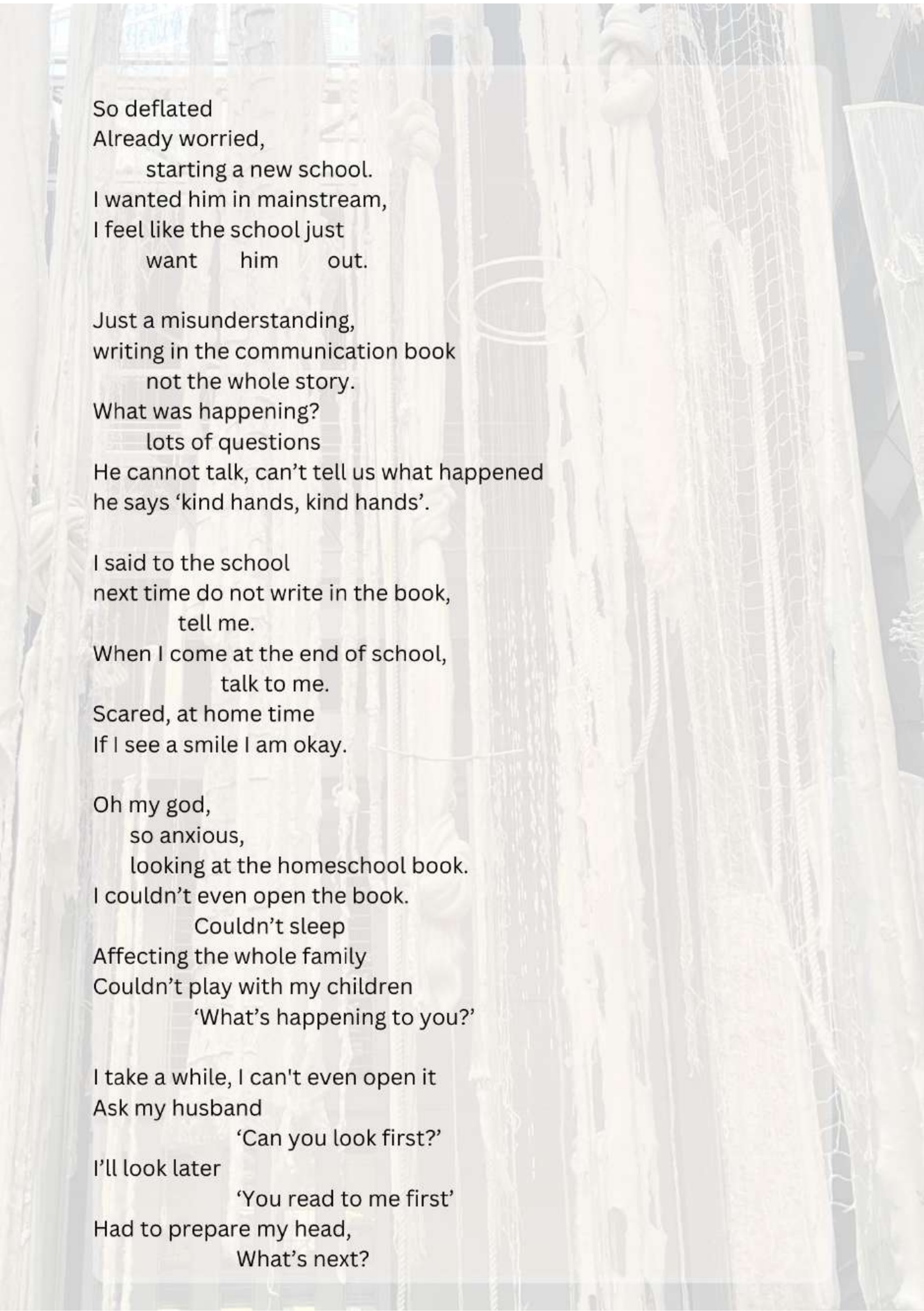
[79] As discussed further in Chapters Nine and Eleven, both can impact on the decisions mothers might make about their child's inclusion and education.



So deflated
Already worried,
starting a new school.
I wanted him in mainstream,
I feel like the school just
want him out.

Just a misunderstanding,
writing in the communication book
not the whole story.
What was happening?
lots of questions
He cannot talk, can’t tell us what happened
he says ‘kind hands, kind hands’.

I said to the school
next time do not write in the book,
tell me.
When I come at the end of school,
talk to me.
Scared, at home time
If I see a smile I am okay.

Oh my god,
so anxious,
looking at the homeschool book.
I couldn’t even open the book.
Couldn’t sleep
Affecting the whole family
Couldn’t play with my children
‘What’s happening to you?’

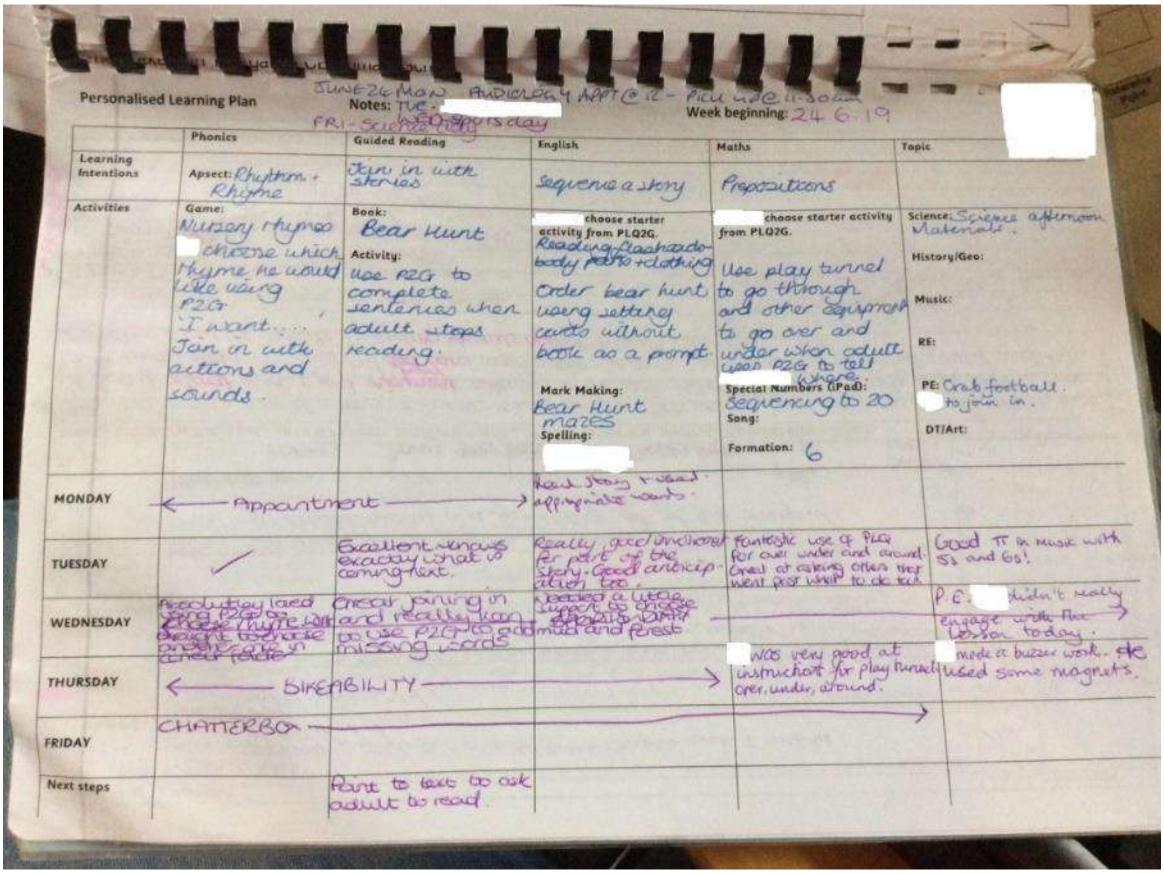
I take a while, I can't even open it
Ask my husband
‘Can you look first?’
I’ll look later
‘You read to me first’
Had to prepare my head,
What’s next?

Transcript poem ‘I couldn’t even open the book’

10.7 Home-school communication books

The use of home-school communication books or diaries for disabled pupils is often cited as an example of good practice for schools supporting parent partnership and engagement (Runswick-Cole, 2016; Murray, 2000). The completion of a home-school diary is a well-established practice, where teachers use the diary to quickly 'communicate the day to parents who aren't at the school gates' (Spear et al., 2022:1254). The diaries are intended to 'foster parental involvement by keeping parents informed' and they can be seen as a 'lifeline for parents' whose child has communication needs (Spear et al., 2022:1254-5). As Runswick-Cole (2016:unpaginated) describes, they are 'particularly useful for pupils who are unable to tell their parents about their day at school because they have difficulties with spoken language or because they struggle to recall events hours after they've happened, or for children who travel to school by bus or taxi and whose parents have no regular face-to-face contact with their teachers'. As well as teachers writing in the books, parents can also respond to comments or discuss things that are happening at home, including how parents are supporting their child's education (Spear et al., 2022). They form part of a wider communications strategy which might include parents' evenings, home-school agreements and discussions in the playground (Runswick-Cole, 2016).

However, home-school diaries are not necessarily unproblematic. Harris & Goodall point out how written communication can be 'major barrier' for parental engagement, especially those who have lower levels of literacy (Harris & Goodall, 2008:285). Spear et al. (2022:1256) describe how some teachers find writing in the book a 'distraction' or possible 'waste of time', as parent engagement was seen as a 'burdensome' task which could result in 'irregular communication and perfunctory messages from teachers'. Sometimes messages are not written in books or diaries might only contain unsympathetic messages of 'disappointment' (Hodgson & Ramaekers, 2022:186). Alternatively, they might present a stark lists of incidents (Mann et al., 2020:352). Accordingly, some parents report that they avoid writing in the diary and do not read messages from the teacher, which can reduce the opportunity for positive parental engagement (Spear et al., 2022). These books, as you can see in the examples below from Anne and Faith who used these as their conversation starters, show how the design of these books frequently encourages only one-way communication, where teachers report on the day or ask parents for information or support. This aligns with Warnock's approach to parent partnership, where parents are there to support the professional role and expertise of teachers (DES, 1978; Green & Edwards, 2021).



Personalised Learning Plan

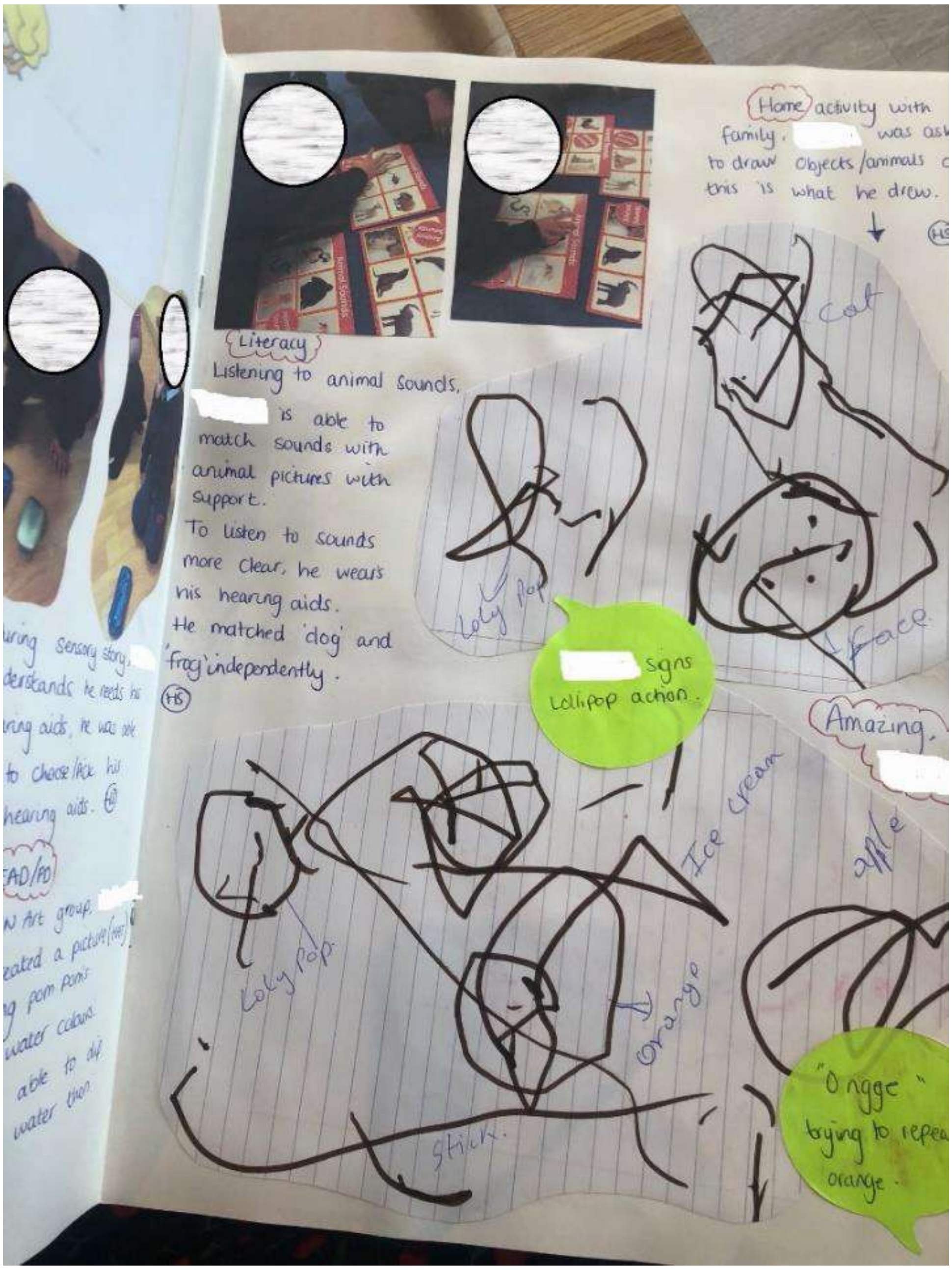
Notes: JUNE 24 MON AUDIOLOGY APPT @ 12 - PICK UP @ 11.30am
TUE - [redacted]
FRI - [illegible] ASD sports day

Week beginning: 24.6.19

[redacted]

	Phonics	Guided Reading	English	Maths	Topic
Learning Intentions	Apsect: Rhythm + Rhyme	Join in with stories	Sequence a story	Prepositions	
Activities	Game: Nursery rhymes [redacted] choose which rhyme he would like using P2G 'I want....' Join in with actions and sounds.	Book: Bear Hunt Activity: Use P2G to complete sentences when adult stops reading.	[redacted] choose starter activity from PLQ2G. Reading flashcards - body parts + clothing Order bear hunt using setting cards without book as a prompt. Mark Making: Bear Hunt mazes Spelling: [redacted]	[redacted] choose starter activity from PLQ2G. Use play tunnel to go through and other equipment to go over and under when adult uses P2G to tell [redacted] where. Special Numbers (iPad): Sequencing to 20 Song: Formation: 6	Science: Science afternoon Materials. History/Geo: Music: RE: PE: Crab football. [redacted] to join in. DT/Art:
MONDAY	← Appointment →		Read story + used appropriate words.		
TUESDAY	✓	Excellent - knows exactly what is coming next.	Really good/anchored for part of the story. Good anticipation too.	Fantastic use of PLQ for over under and around. Great at asking others that went past what to do [illegible]	Good TT in music with 5s and 6s!
WEDNESDAY	Absolutely loved using P2G to choose rhyme [illegible]	Great joining in and really keen to use P2G to add missing words	Needed a little support to choose [illegible] mud and forest	→	P.E. [redacted] didn't really engage with the lesson today.
THURSDAY	← BIKEABILITY →			[redacted] was very good at instruction for play tunnel over, under, around.	[redacted] made a buzzer work. He used some magnets.
FRIDAY	CHATTERBOX →				
Next steps		Point to text to ask adult to read.			

Image 20: James's home-school diary



uring Sensory story, [redacted]
derstands he needs his
ring aids, he was able
to choose/lick his
hearing aids.

EAD/PD

N Art group, [redacted]
eated a picture
ng pom poms
water colours
able to dip
water then

Literacy

Listening to animal sounds.
[redacted] is able to match sounds with animal pictures with support.
To listen to sounds more clear, he wears his hearing aids.
He matched 'dog' and 'frog' independently.
HS

Home activity with family. [redacted] was as
to draw objects/animals c
this is what he drew.
↓ HS

[redacted] signs Lollipop action.

Amazing. [redacted]

"Ongge" trying to repea orange.

Image 21: Brave's home-school diary

The documentation that is produced and collected matters, how it is used matters, and how we approach meaning-making matters (Lenz Taguchi, 2010). Text, photographs and notes in home-school books can be understood as a '*material-discursive apparatus*' (Lenz Taguchi, 2010:63, original emphasis). As ‘material observations’ that are active agents in generating knowledges and what matters (Lenz Taguchi, 2010:63).

Photographs, sketches or written words can ‘put things in motion by means of its own agentic force and materiality’ (Lenz Taguchi, 2010:63). They are a ‘constructed cut of an event’ which excludes other ways of knowing, depending on what possibilities arise from the cut (Lenz Taguchi, 2010:68). As Lehrer (2018:292) describes, the daily reports sent home from school can therefore contribute to constructing an image of the ‘good’ child, one who ‘is happy and conforms to adult behaviour expectations’ and who ‘participates in a multitude of activities’. This can be seen in both Brave’s and James’s diaries, which describe particular events from the day, whilst simultaneously reinforcing normative expectations of what children *should* be doing. Interestingly Brave’s book is written in a way that suggests it will be shared with him at home too, with the comment ‘Amazing Brave!’ written below his drawing, alongside reports of work he had completed at home and school.

As well as the child and parents being constructed through these books, the educator is too. Lehrer suggests that home-school books aim to ‘position the educators as providing a stimulating and varied educational programme, being concerned about the child’s well-being, caring about the parent, and attempting to collaborate with parents when their careful observations identify issues of concern’ (Lehrer, 2018:293). Therefore, when the child fails to engage, it is the child who is lacking or failing, rather than the educator. For example, it is reported in his diary that James did not engage well in PE, but there is no discussion as to whether the lesson was suitably adapted or why James might not have engaged. Instead, the inference is that James just chose not to engage. Home-school books can also be seen to construct and position parents too, as they are expected to conform to school expectations of what good collaboration looks like, as well as being ‘subjugated to [the] teacher’s constructions of their children’ (Lehrer, 2018:296) as potentially lacking or not-belonging in each space.

Although parents, including those in this inquiry, will frequently store these home-school books as ‘keepsakes’ (Lehrer, 2018), home-school diaries do not generally form part of the paperwork that is used as ‘evidence’ for EHCP needs assessments or annual reviews. They are seen as more day-to-day objects, documenting what has happened during the school day or at home informally. This does not, however, mean that they are not agentic, that they do not set things in motion. Indeed, I would argue the opposite is true. Home-school books can be understood as ‘affectively loaded phenomena’ that are ‘capable of carrying, containing, or inciting affective energies’ when used in ‘webs of social relation’ (Navaro-Yashin, 2007:81) such as relationships between home and school. It is these energies, the potentialities and affects that can be engendered (Navaro-Yashin, 2007), that I now explore further.

10.8 Vignette

Sita emailed me due to feeling ‘deflated’, describing how, following his move to Junior School, Kiran had started to display challenging behaviours at school. She described in her email:

> *You know, how much I wanted Kiran to be in mainstream and the benefit of it. But I feel like the school just want him out*.

She explained that she had a meeting with the school soon but did not know what to say. She explained further,

> *I don't know how people get all the strength to fight. I feel so tired and don't know who to go to for more advice in helping me fight for my child*.

Following the email, I sent Sita some resources from the Down's Syndrome Association about behaviour and the training courses available for educators, and suggested we could have a call if she wanted to discuss anything further. She asked whether this situation she found herself in could be included in the research inquiry so that it could benefit others.

It transpired that Kiran's one-to-one support finished 3pm daily, but the school day finished at 3.10pm. In the final ten minutes of each day, he was left on his own with an iPad to play on. Other children wanted to play on the iPad too, but Kiran pushed them away, not having the language capabilities to explain why he had the iPad. A teaching assistant wrote a short message in the home-school book to tell Sita about the incident, saying '*Kiran pushed a child, can you speak to him'*. Sita described how her immediate response was '*I do not know all the rights for my child… I think they will just like try to, like they will just try to like, no, no, we just get him out of this school now you know'*.

Sita explained how she was already worried about Kiran's move to Junior school:

> *I cried, I was so worried, like, I mean, is he gonna cope it's a new school, a new teacher, new TA's you know that. I mean, are they gonna understand him. All those*

> *things. Yeah are they gonna listen to me, all those things as well.*

Even though the meeting with the school went well and they agreed to put a plan in place, the initial communication in the book continued to affect Sita. She described '*it was so anxious even looking through the, as soon as you come back from school, just looking at the homeschool book'*. The presence of the book resulted in sleepless nights, and it had an impact on the whole family:

> *I was honestly so down couldn't sleep. My, oh my god, it affected the whole family, my husband's like 'what's happening to you?' And then I couldn't even play with my other children, I just don't want to do anything.*

When we spoke two months later Sita continued to describe how:

> *sometimes I take a while to open the book. I can't even open it, have to ask my husband can you look first, and then I'll look at it later on. So you will have read to me first and then I'll go, okay*.

10.9 Affective material encounters

It is important to attend to the level of impact that every day 'ordinary affects' can have, the small events that happen daily but that can be experienced as 'palpable' (Stewart, 2007:3) and felt as 'real' (Navaro-Yashin, 2007:81). For example, mothers of disabled children might notice people looking at their child as they go about their everyday business, a feeling of being othered that sticks with them on future trips out of the home. Stewart (2007:12) describes how the everyday and the ordinary are always in motion, charged with potential, waiting for something to happen that will 'compel a response', forcing us to take a closer look. Had Sita not described her experiences in our conversations, I might not have been drawn to thinking about these books even though Faith and Anne both brought the books I shared above as their conversation starters. However, as Stewart (2007:19) articulates, we can have a 'wake-up call' when something 'pops up out of the ordinary'. We can feel the 'pull' of the ordinary (Stewart, 2007:29) and this pull can 'tell the story of inclusion or exclusion, mainstreaming or marginality' (Stewart, 2007:43).

Affective encounters with material objects, such as the one Sita had when she read the comment in the home-school book, have the potential to attune us to promises or threats, to mark our belonging or non-belonging, and to either 'keep us stuck' or help us to move forward (Dernikos et al., 2020:6). Affect occurs 'before conscious thought', as 'infinite potentialities' emerge and unfold, 'registering intensities' in and between bodies and objects (Dernikos et al., 2020:8). Life trajectories can be changed, as we respond to these affective intensities and attend to the 'possible and the threatening' (Stewart, 2007:12). Further, as Dernikos et al. (2020:18) describe, '[a]tmospheres of inclusion and exclusion' are 'made up through material practices and regulatory relations of everyday school objects', such as the home-school book. Sita's immediate acutely felt sense was that the school, in their brief reporting of the incident, wanted to exclude him. The affective encounter drew attention to how Kiran might not really belong in that school, that his inclusion was conditional. When the threat of exclusion came to the fore it had an impact on Sita's capacity to act both in relation to the school and as a mother to her other children. Affect can be 'communicated through tone, volume (loudness/quietness), body language, color choice, or texture: things that extend beyond words' (Dernikos et al., 2020:146). It can also be communicated through absences. In Sita's situation, the lack of detail in the home-school book contributed to the affective encounter. Had there been greater description or reassurance that the school would put support and strategies in place, then the book might not have registered the same affective intensity.

Documents can incite fear and can also evoke the ‘imaginary of being haunted’ (Navaro-Yashin, 2007:83). Dernikos et al. (2020:11) describe how ‘affects haunt our lives’. Often haunting is thought to relate to individual or collective histories, however, as I will further discuss in Chapter Eleven, it is possible that the future haunts us too. For Sita, the potential of Kiran’s exclusion is always with her, a haunting. Navaro-Yashin (2007:82-4) describes documents as having ‘phantasmatic power’ and ‘psychical weight’. Zarabadi (2020:72-4) similarly describes how ‘affective intensities of threat’ are materialised through the ‘uncertainty and vagueness’ of the event, within a ‘phantomatic space’ where abstract threats are felt as real. Whilst Kiran was not excluded from school for the incident detailed in the book, the documateriality of the home-school book causes extreme levels of anxiety in Sita, as the threat of Kiran’s exclusion becomes palpable. As Massumi (2010:53) describes, when discussing how threat is felt:

> Even if a clear and present danger materializes in the present, it is still not over. There is always the nagging potential of the next after being even worse, and of a still worse next again after that. The uncertainty of the potential next is never consumed in any given event. There is always a remainder of uncertainty, an unconsummated surplus of danger. The present is shadowed by a remaindered surplus of indeterminate potential for a next event running forward back to the future, self-renewing.

Affect is located ‘in the midst of things and relations’ and ‘in the complex assemblages that come to compose bodies and worlds simultaneously’ (Seigworth & Gregg, 2010:6). Our capacities to act are produced through the flows of affect between ‘multitudinous relations from physical, biological, cultural and abstract realms' connected in assemblage (Fox & Alldred, 2017:99). As Dernikos et al. (2020:6) describe, 'each entity within the assemblage acts on the subject—albeit not equally'. Affective encounters, such as the one Sita experienced, emerge from the specific material entanglements in the event, within an ever-changing assemblage 'of both material and immaterial, human and nonhuman forces' (Dernikos et al., 2020:19). Here Sita is not operating as an autonomous conscious individual, rather she is becoming within an assemblage of multiplicities.

Sita still feels the affect of the threat of exclusion every time she sees the unopened home-school diary. As Massumi further describes, threats that do not materialise are 'not false', rather the 'affective reality of a past future' is truly felt, deferred but 'forever open' (Massumi, 2010:54). The ghost of future exclusion[80], which has ever been present, materialises through the home-school book. The book haunts because of its affective 'threat-potential' (Massumi, 2010:58). Yet this temporal feeling of threat might be elusive and difficult to pin down, it might just be sensed as a threat, a sense of foreboding (Zarabadi, 2020), impossible to clearly articulate. Whilst the presence of the book creates a visceral reaction in Sita, she might not connect this with decision making about Kiran's education placement. The ongoing affect and real threat of exclusion might result in her making a pre-emptive move to specialist provision to prevent this expulsion from happening. As Sita went on to discuss, she now wondered whether maybe a resourced provision might be a more suitable setting for Kiran. The home-school book is just one component of the assemblage (Deleuze & Guattari, 1987) that allows for the phantom threat (Zarabadi, 2020) of Kiran's

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[80] I return to discuss haunting and ghosts in Chapter Eleven.

exclusion to materialise. This demonstrates the importance of paying attention to bodily responses to material objects such as the home-school book when considering the decisions that parents might make about their child's education.

This brief exploration of documentation practices draws attention to 'micropolitical interactions between assembled relations' (Fox & Alldred, 2017:179) to demonstrate the importance of attuning to affect within processes that are often posited to be objective and rational. By paying attention to documentation, it becomes possible to recognise what documents can and do '*do',* and the potential impact on inclusion. Rather than seeing documents, books and images as 'tools of humans', it is important to recognise how matter comes to matter (Kummen, 2014:813). As Lenz Taguchi describes, 'material objects and artefacts can be understood as being part of a performative production of power and change in an intertwined relationship of intra-activity with other matter or humans' (Lenz Taguchi, 2010:4). When we recognise this, it becomes important to understand how 'documentation practices are entangled in how teachers, families and children are creating and transforming what kinds of knowledge are valued, in particular the value placed on the notion of belonging' (Albin-Clark, 2019:134)[81].

Instead of considering the issues within the SEND system as a problem of 'top-down' power (Fox & Alldred, 2017:178), thinking differently about documentation practices by both parents and professionals can help us recognise the importance of exploring assemblages

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[81] I discuss belonging further in Chapter Eleven.

and affects in the ongoing inclusion and exclusion of disabled children in education. As Hohti (2018:13) describes, it is important for us to recognise how 'ideas and ideologies come to us in materially entangled ways', including through documentation practices. Indeed, it could be argued that it is the 'materially entangled nature' (Hohti, 2018:13) of the SEND system that makes it resistant to change, as individuals are produced and fixed through documentation practices.

Documents as material matter 'have force and power to transform our thinking and being in a particular space or in the world at large' (Lenz Taguchi, 2010:4). Documentation can change mothers' beliefs about what is possible or desirable for their children and can shape the way that educators approach the education of disabled children. It is therefore necessary to recognise the affective capacity that documentation has, and the way that this can either enable or constrain capacities for parents who are attempting to secure the inclusion of disabled children in education. When documentation is recognised as a 'performative agent' that will 'put things in motion by means of its own agentic force and materiality', new possibilities and choices may emerge for documentation practices (Lenz Taguchi, 2010:64).

Of course, 'documateriality', as discussed in this thread, is only one part of the assemblage, for instance in an annual review meeting there may well be a pile of paperwork, alongside a name badge saying 'mum', child-sized chairs for parents to sit on and a seating arrangement that suggests a them and us situation. It is therefore important that we consider how various forms of documentation come to matter as they intra-act with the other 'things, matter, artefacts, materials, furnished environments and architecture' (Lenz Taguchi, 2010:65) that might not normally be considered as part of the EHCP process. Home-school communication books or memes produced by parents are apparatuses for meaning-making that matters, and therefore they can equally play a role in producing knowledges and possible futures for disabled children alongside the reports produced by professionals.

11. THREAD - BELONGING

11.1 Introduction

> *She said what do, what do you want for Zebedee? And I thought it was such a good question. My answer, I basically said communication, friendship and belonging which is essentially inclusion isn't it?* (Jayne)

> *There's a Tesco Delivery Man who comes here, and he's obviously known us a long time in and out, and he said to me early on he said I've got a friend with Down syndrome, he said. And he says, I go down the pub with him every single Friday night… and he says, he's fantastic company… and we have a really good night with him… And I've kind of hung onto that and I've kept saying to the headmistress what I want one day… my dream is at 18 somebody will come and take Ethan and go, I'll take you down to the village for your first pint* (Emily)

One of inclusion's frequent conceptual bedfellows is 'belonging'. As Connor & Berman (2019:933) describe, the concept of belonging is 'a vital part of justifying, conceptualising, and actualising inclusive education'. Vandenbussche & de Schauwer (2018:970) further suggest that there is a need to put a sense of belonging 'at the core of the inclusion debate', and Mahar et al (2013:1027) describe how feeling a sense of belonging has been identified as a core dimension of the social inclusion of persons with disabilities. The concepts of inclusion and belonging frequently appear unquestionably synonymous with each other in discussions about the education of disabled children, where belonging is a 'shadow concept' (Bissell et al., 2019:2) of inclusion. It is always there but the attention tends to be on what it means for disabled children to be included, rather than any questioning of what it means to belong. As previously discussed, inclusion is a contested concept, and it is important to recognise here at the outset that belonging is even more 'vaguely defined' (Antonsich, 2010:645).

As Mahar et al. (2013:1027) describe, there is a vast body of literature discussing a ‘sense of belonging’ across several disciplines, yet there is still no apparent consensus as to how it is defined. Possibly due to the lack of conceptual clarity, despite each having a ‘complex character’ (Mattes et al., 2019:300), the relationship between the two concepts of belonging and inclusion in relation to the education of disabled children is rarely theorised. However, as Slee (2019:910) describes, perhaps it is naïve to accept ‘‘belonging’ as a conceptual and practical precondition or element of community and inclusion’. It is therefore important to closely consider the relationship between belonging and inclusion, as I now proceed to do.

Belonging is ‘a concept that pervades everyday talk’ and is seen to be of ‘fundamental importance to people’s lives’ (Wright, 2015:391). As Tsalapatanis (2019:13) describes, belonging is treated ‘unproblematically’ yet it ‘has always been difficult to convey’. Indeed, the term ‘belonging’, as Nagel (2011:108) describes, ‘conjures up a variety of meanings – some quite positive, reflecting feelings of warmth, security, and being at home; some perhaps more ambiguous, hinting at exclusion, conformity, and struggle’. It can mean ‘to fit in’ and to be a member of a group, but also can relate to what is proper, suitable, or appropriate (Nagel, 2011:108). It frequently has normative underpinnings where it becomes possible to describe which people belong where. It is both relational and imbued with power (Tsalapatanis, 2019). Practices of boundary making undertaken by others will determine the spaces in which we can be seen to belong or not belong, meaning that ‘we alone cannot dictate the terms under which we belong or don’t belong’ (Tsalapatanis, 2019:16). Through these boundary making practices, some pupils are constructed and produced as belonging, whilst others are marked as not belonging. Belonging and not belonging can be at the level of friendship groups, a specific lesson or classroom, or within the whole school environment. In other spaces, the same individual might be seen to valued and welcome, without needing to change their behaviours or identity to fit in.

Yet despite its complexity, as Antonsich (2010:644) describes, belonging is seen as ‘intuitive and common sense’ which means ‘that people generally would not bother asking their interlocutor “what do you mean that you belong here?”’. Wright (2015:391) concurs, claiming that paradoxically ‘the term is at once slippery and axiomatic, flexible and self-evident’, further suggesting that ‘We all know what it means to belong, or to not belong, don’t we?’. However, as Nagel (2011:110) asserts, the issue of belonging is complicated; individuals will face multiple experiences of acceptance and rejection, and belonging can therefore be seen as incomplete, tenuous, and conditional. Experiences of belonging are shaped at various levels and enacted in multiple spaces, involving negotiations between different groups and structured through laws, policy, and norms (Nagel, 2011:110). Belonging is contextual and it can also ‘mean different things to different people’ and is ‘used in disparate ways’ (Wright, 2015:392), which means that it becomes important to attune to how the notion of belonging is deployed in relation to inclusion for the education of disabled pupils.

Baglieri et al (2011:2123) state, ‘[i]magining schools as places where children can find belonging and community conjures values and ideas with which few would argue’. It is because of this taken for granted status, it is necessary to ‘attend deeply to the ways that belonging is constituted’ (Wright, 2015:392) and the impact this has on the inclusion of disabled pupils in education. It is evident within previous research (Erwin & Soodak, 1995; Swart et al., 2004; Grech & Grech, 2010, Lalvani, 2013; Flood, 2019) that parents frequently discuss belonging when talking about educational placements for their children. Yet, whilst the concept of belonging is 'increasingly used to critically approach inclusion debates', there remains 'limited research about the ways that families connect with perspectives on belonging' (Robinson & Notara, 2015:726). Because belonging is a '"complex and multi-faceted" affective phenomenon' that can be described in several ways (Craggs & Kelly, 2018:1), it is important not to assume that the close relationship between 'inclusion' and 'belonging' is either natural or desirable. Instead of accepting it as self-explanatory and commonly understood, it becomes necessary to 'scratch beneath the surface' of belonging (Bissell et al., 2019:2) and what it produces.

When we push the concept of belonging 'beyond the conceptual confines of identity' and engage with more 'pluralistic notions of being with diverse others' it becomes possible to see that belonging is not necessarily 'a given' (Bissell et al., 2019:4). There are many ways that people can experience and understand what it means to belong; it can be a sense, a practice or a space. Belonging can also be recognised as being performative, 'uncertain and provisional', 'ambiguous' and 'fragile' (Bissell et al., 2019:4-5). Importantly, it becomes possible to see that the often intensely experienced feelings of 'not quite fitting' can cause discomfort and a 'sense of unease' that can become 'affirmative and productive in terms of social change' (Bissell et al., 2019:5). As I will go on to show, the sense of not quite fitting anywhere is one keenly felt by many mothers of disabled children when thinking about the most suitable education setting for their child. I therefore intend to do some scratching to think about what the notion of belonging produces in relation to the inclusion or exclusion of disabled children in education before I move on to consider how we might conceive belonging differently and what this might mean for the education of disabled children.

11.2 Why explore belonging?

Early in this PhD journey, my friend Neetha suggested that I might want to read Lalvani's research exploring parents' experiences and views on the inclusion of disabled children in the United States. Lalvani has a daughter who has Down syndrome and much of her research engages with the decisions that parents make about their child's education. Whilst immersing myself in her work, I particularly found myself drawn to her discussion of belonging in relation to inclusion (Lalvani, 2009;2013). Lalvani (2009:148) describes, 'when mothers discussed the nature of classrooms or their preferences for either inclusive or segregated education, they often expressed beliefs about where their children would be most accepted by others or where their children "belong"'. The mothers who advocated for inclusive education described belonging in terms of their child being 'included in day-to-day life' and their 'right to be included' or the 'right to access the same educational curriculum as everybody else' (Lalvani, 2009:148-9). Lalvani describes how some parents saw general education as a 'fundamental right' for all children, and that inclusive education would 'prepare their children to participate in society as adults… or help them to become more integrated in their communities', with one parent describing how her daughter must learn to 'fit into the real world' and 'relate to everybody, not just her quote-unquote disabled peers' (Lalvani, 2013:439). The mothers of children who were in specialist placements saw these spaces as 'places of belonging', as somewhere that their child would 'fit in' (Lalvani, 2009:150). They described how their child would be understood and accepted within the group, as everyone would be just like each other; one mother described it as being ‘like the land of misfit toys where everyone is in it together’ and where differences do not ‘become noticeable’ (Lalvani, 2009:151). Specialist provision was therefore seen to offer a ‘welcoming’ environment that provides ‘safety and protection from failure or rejection’, or as one mother in Lalvani’s study described, it offers parents their own ‘security blanket’ as they know that it is a place where their child will be understood and is not expected to be ‘perfect in a way that they might in a typical class’ (Lalvani, 2013:440). Here, specialist education settings are imagined by these mothers as ‘places of unconditional acceptance’ that provide ‘opportunities for membership to a group’ (Lalvani, 2009:151). Although Lalvani does not explicitly state this, the narratives she describes can be understood as being underpinned by two different conceptions of belonging that are not necessarily in binary opposition to each other, which are worth exploring further.

When you conceive belonging connected to rights, this is very different to having a sense or feeling of belonging in a place with others who are like you. As Antonsich (2010) discusses, belonging can be used as a synonym of a particular identity, or it can be used in association with the notion of citizenship. We see both being discussed in Lalvani’s findings. Lalvani suggests that the two groups of mothers ‘differed in their conceptualizations of the groups to which membership was sought’ (Lalvani, 2013:444). There are various assumptions underpinning these two different conceptualisations. For example, when belonging is understood as an ‘entitlement’ to rights or citizenship, this ‘involves privileges and allegiances, and relates to civil and political rights’ (Mattes et al., 2019:302), which can be seen as a ‘politics of belonging’ as discussed by Yuval-Davis (2006:197). This is an ideological or political position, that shifts away from belonging as a personal matter to a social matter related to rights and responsibilities, legal status and formal structures of belonging and participation in society (Antonsich, 2010). Whereas when belonging relates to a place where ‘an individual can feel “at home”’ the focus of attention becomes the need to secure ‘comfort, security, and emotional attachment’ (Antonsich, 2010:646). However, Lalvani’s study does not expand on the mothers’ different understandings or conceptualisation of what it means to belong, nor the assumptions underpinning them. In relation to how ideas relating to belonging impact what mothers see as a possible or desirable education setting, this feels useful to explore, especially as Lalvani describes how:

> many of the same mothers who strongly resisted notions of otherness in their conceptualizations of disability, in their interpretations of their motherhood experiences, and in their descriptions of their children with Down syndrome, when confronted with important education related decisions, succumbed to ideological notions of a child with Down syndrome as other. When making decisions concerning schooling placement, they seemed to focus on those needs of their children with Down syndrome that rendered them different from children without disabilities rather than on those that could be considered common to the education of all children (Lalvani, 2009:154).

If belonging was something that mothers feel is important in their decision making, a deeper exploration of how belonging or not belonging is both conceived and experienced can provide new knowledge about why mothers of pupils who have Down syndrome may choose a specialist placement for their child despite resisting notions of otherness in all other aspects of their lives[82]. Curious, I emailed Professor Lalvani to ask her if she had considered

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[82] See also earlier discussions about how mothers of disabled children will also be caught up in ableist discourses.

these different conceptions of belonging in any further detail and why both groups of mothers had used notions of belonging to explain the decisions that they had made.

She replied to say:

> *So, belongingness does indeed seem to be a theme across all my research - or, I should say, mothers seeking belongingness for their children. Your question is a good one, and I cannot say I have the exact answer, because it was not clear from the study I did why some went one way and others, another way, in seeking the SAME thing (as you so correctly pointed out)!*

She further added *'I actually love your question, and it is making me think...'* (P. Lalvani, personal communication, 20 September 2020). We subsequently arranged a Zoom call to discuss this further. It was following this conversation, for which I remain grateful to Professor Lalvani for her time, I recognised the importance of exploring belonging further, specifically in relation to mothers' decision making re school placements.

In this thread, I will first consider how belonging has been discussed in relation to education, to demonstrate how inclusion and belonging are often discussed in tandem, demonstrating how their close conceptual relationship might result in mothers feeling that a separate specialist setting is best for their child. I will draw on examples from the inquiry conversations with mothers as part of this discussion about belonging, even though we did not discuss belonging explicitly. I will then step back to consider the broader concept of belonging and how this is generally understood within academic literature, before returning to explore inclusion when alternative approaches to belonging are brought into play as I draw on our conversations to further inform and illustrate the theoretical discussion within this chapter.

They speak of him as invisible. Not normal
Judged by his condition
They see no progress
They have very little capacity, are stretched very thin
They say it's not their fault
They are beginning to wonder if this is the right place for him
They have given up

She flippin' knew my name
She just always calls me 'mum'

They allocated him a school place
They had not discussed it with me
A big mess up. Massive admin error
They're so overloaded. Drop the ball
They thought he was in school.
Waiting for my letter to arrive
Nothing arrived...

She changed everything; she just made me think
She was like, mainstream, that's what he needs
She had that insight
Motivated me to fight
This child needs to be in mainstream school
That's what he needs!

She hates him, she hates him!

Parents ignore me
look away
They are pitying us

You are so brave!

They don't listen, just hang up
Ignore me, don't return my calls
They don't believe me
They are the teacher. The local authority.
They are the professionals, the experts
What they say is valued.

She took him under her wing,
Seemed to get it, went above and beyond
Put her faith in him
Went out of her way
To make it work
She was amazing

They laughed at me
They tell me I don't understand
They treat me like my son. But I understand everything.
They withhold information, try to confuse me.
They're looking at me thinking, what's she on now?

You are so brave!

They are too busy to take calls and emails
Do not attend EHCP reviews
Do not adhere to statutory deadlines
Do not produce the report
Do not send paperwork
Do not respond to requests for information
Do not reply. Nobody replies

I know immediately
From the conversation
The body language
'Ahhh another child with an EHCP'

They sent me a lovely video
of him taking the register

They were worried we were going to send him there
Afraid
Not enough staff
Waiting for training
Haven't got the time
Funding has been cut
They say they can't cope. They are not ready for him
'There's no places you know!'

I know immediately.

They treat him differently,
babying him in a kind way
'We love having him here'
Is he becoming like the school pet or something?

She said
'I want to tell you about a meeting I had
A child engaged in a mainstream school'
She said
'I think he might cope in mainstream'

Who is an expert?

She doesn't send me the timetable
She doesn't send me anything for this year
She says you don't understand, they are at different levels
She doesn't listen

I'm just relying on lots of different opinions
and I don't know who to trust anymore…

Never spoken to me
Never replied to an email
Never engage with me
Avoiding difficult questions
They think we're going to be trouble.

They never reply.

Transcript poem 'They'

11.3 Where do disabled pupils belong?

‘Belonging’ is a recurrent and persistent theme within research literature discussing parental experiences and perspectives relating to the inclusion of disabled children in education. Erwin & Soodak (1995:139) described how ‘themes such as a sense of belonging, being part of the group, and not being separate’ were consistently evident in parents accounts of what they consider to be inclusion. They explained how parents of disabled children who were seeking inclusive education wanted their child to ‘fit in’ and ‘be as accepted by others as they were by their own families’ (Soodak & Erwin, 1995:265), and furthermore they believed that ‘segregated education denotes exclusion and degradation’ which Soodak & Erwin (1995:267) claim is the ‘antithesis of what they most want for their children – a sense of belonging’. This aim to secure a sense of belonging via inclusion is, of course, in contrast to the parents in Lalvani’s study, as discussed above, where those who were choosing specialist placements were doing so because they felt it would offer a sense of belonging for their children.

Similarly, the parents in the study undertaken by Swart et al. (2004:90) described how they chose mainstream education because they ‘felt that their children had the right to have a place in society, to attend the same neighbourhood school with friends and to participate in the same community activities’. As well as wanting ‘to influence society's views on disability: “We did the right thing, because the world must see them”’ parents saw mainstream education as the place in which their disabled child would learn to ‘manage the demands of society’, which would help them to live in society when they were older (Swart et al., 2004:89-90). They faced the ‘hard reality’ of having to decide between their child being ‘protected in a safe situation’ or helping their child to ‘adapt in a normal situation’ (Swart et al., 2004:91).

Rogers (2007:59) suggests that the promotion of ‘inclusive’ education does not acknowledge the ‘suffering’ that can occur with the ‘desire to make everyone “fit” within a certain mould’. Cigman (2007:785) contends that parents who advocate for inclusion see the suffering of some children in mainstream school as inevitable within a ‘process of struggle’. She claims parents seeking inclusion believe that:

> even if some children feel excluded within inclusive institutions, it is possible that they should become included. It is possible, that is, that they will come to enjoy the goods of mainstream education: the sense of belonging to a community, the right to participate in shared programmes of learning, the opportunity to prepare for adult life in an inclusive society, and so on (Cigman, 2007:285).

She sees this as a form of ‘seductive thinking’ that invokes the ‘possibility clause’, based on the assumption that everyone can be included, which is ‘essentially an article of faith’ (Cigman, 2007:785). She claims, however, that there is no empirical basis for this possibility clause and argues that there is a great deal of evidence showing that ‘that some children not only are unhappy in mainstream schools but seem destined to remain so given our growing understanding of the nature of their difficulties’ (Cigman, 2007:786).

Similar links between belonging and safety, alongside suggestions that inclusion is ideological and impossible, are also evident within Warnock’s clarification of her views on inclusion from 2005 onwards. Warnock (2010:36) suggested that the deployment of a human rights argument for inclusion can ‘lead to an insensitivity to [the child’s] needs’. Instead, she suggested, it is the right to learn and to feel that they belong that must be defended, rather than the right to be in the same environment as everyone else. She claimed this is because there are many children who ‘can never feel that they belong in a large mainstream school’ (Warnock, 2010:34). Instead, she argued, decisions relating to educational placements must be made based on evidence ‘on how children with different disabilities flourish, or fail to flourish, in different settings’ (Warnock, 2005:17). She therefore called for the ‘proper inclusion of all children within one educational enterprise’ (Warnock, 2010:42), where they can ‘pursue the common goals of education in the environment within which they can best be taught and learn’ (Warnock, 2010:44). She suggested that this does not mean that everyone is necessarily educated ‘under the same roof’ (Warnock, 2010:32). To support her argument for separate specialist education provision for some disabled children, Warnock explicitly drew together notions of belonging with the need to protect vulnerable students. She argued that the ‘concept of inclusion must embrace the feeling of belonging, since such a feeling appears to be necessary both for successful learning and for more general well-being’ (Warnock, 2010:14).

Warnock was particularly concerned about ‘exclusion within inclusion’, that is, ‘exclusion within institutions’ (Cigman, 2007:785). She described how many students ‘are not included at all’ in mainstream education environments, and ‘suffer all the pains of the permanent outsider’ (Warnock, 2010:37). She described these children as ‘vulnerable’ or ‘fragile’ (Warnock, 2010:36) and asserted that mainstream school can be a painful and traumatic experience for them. Accordingly, specialist settings would be more suitable so that they could ‘believe that they are valued’ and ‘feel that there is a society… where they are at home’ (Warnock, 2010:36). This conceptualisation of belonging enables specialist provision for disabled pupils to be seen ‘not as inherently demeaning environments, but as liberating and in the best sense educational environments’ for children (Cigman, 2007:782). Dreyfus (2020) suggests that this is the oxymoron of the special school. Although her son could only be accepted within a specialist provision, she describes how his belonging was ‘equal to a separation’ and that specialist settings can only ever provide ‘a segregated kind of belonging rather than belonging in the school community at large’ (Dreyfus, 2020:26). Whilst many parents might hope for a mainstream education for their child their expectations of their child being included and accepted into the mainstream school environment may not be materialised. As Rogers (2007:63) describes, children who are ‘included’ can be excluded ‘practically, intellectually and emotionally’. Such exclusions, she argues, are ‘caused and compounded by a testing and examination structure, cultural ignorance and misunderstandings about difference and difficulty’ (Rogers, 2007:63).

Practices within schools, such as banding and streaming, continue ‘to reflect hierarchies of belonging and exclusion from the educational main-game’ (Slee, 2019:910), but these structures and their inherent hierarchies are often overlooked when considering what it means to belong (Robinson & Notara, 2015). Instead, if the pupil is unable to meet expectations, for example academic achievement or behaviours, then it is perceived to be something about them that means that they do not belong, rather than the practices, culture and structure of mainstream schools that means that they are understood as being for some children but not all (Slee, 2019). As Baglieri et al (2011:2123) describe, the ‘now banal term inclusion has been so frequently associated with children labelled disabled that its usage reifies taken-for-granted assumptions that the “natural” position of this group is one of *dis-belonging’* (emphasis added). As such, parents of disabled children may come to believe that it is natural that disabled children belong together, that they would be happier in a separate education setting, and that it is better for them (Connor & Berman, 2019).

By way of an example, in one of our conversations, Clare described how she was aware of other children with Down syndrome attending mainstream secondary schools but that they ‘*are usually quite isolated socially and educationally’* and therefore ‘*I just don't think that mainstream is an option*’. She was especially concerned that Thomas’s speech delays would mean he would be ‘*completely isolated’*. George also described how, Ezra ‘*won't be able to do mainstream’*. Although she thought ‘*he would love it’* and he had never faced any negativity to date, she was particularly concerned that ‘*he'll be lost, it'll be friendship groups and that*’. The fear of isolation in the future leads to the idea that specialist provision would be better[83]. Friendships were also important to Clare, who described how:

> *in the last few months, there's just been a few situations where, you know, he hasn't been invited to parties or, you know, I have kind of realised he doesn't get invited to play dates. You know, and I'm sort of struggling to manage my sadness around that now*.

She recognised that the ‘*gulf is really widening socially now’* and this was a major factor for her when thinking about Thomas’s impending move to secondary school.

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[83] I return to discuss how fears of not belonging in the future can shape the decisions mothers make later within this thread.

Slee (2019:916) describes how many parents face ‘painfully real’ scenarios that ‘tell them that their children do not belong’ – for instance their child not being included in birthday parties or being placed within an ‘inclusion room’ rather than the main classroom or being told by a professional that ‘their child would be safer or cared for in another school’. In the case of no invitations, there will be emotional ramifications and a sense of being rejected, potentially for both the child and the parents (Connor & Berman, 2019). Friendships are an important part of our lives, and the lack of playdates results in further separation and isolation. Clare further described how Thomas is ‘*sitting in a class with twenty odd other children and the teacher is teaching all of them, but you know he's not doing what the rest of the class are doing so, you know, is he already being isolated in his lovely mainstream school*?’, before asking:

> *would he be happier in a classroom where he is doing what his peers are doing? I don't know. You know these are the thoughts that flashed through my mind. You know at 500 miles an hour, every second of the day, so it's not that simple.*

George raised similar concerns about friendships ‘*I mean he's got friends and that but especially this year I started to notice when we walked to school, there'll be a few of them who were his friends, but they'll be like oh god its Ezra’.* George was concerned that Ezra’s peers no longer wanted to spend time with him. She described noticing how the ‘*gap gets bigger’* and *‘it just gets harder’.* Such negative personal relationships or a lack of connection to others can be felt acutely as a threat to belonging (Robinson & Notara, 2015).

This sense of isolation can also extend to parents themselves. Sita described how, after Kiran was born:

> *I realised my friendships, just happen to be around the special needs parents only. And I had old friends but that's it, but with the new friends, it was kind of, kind of like difficult. I find it a bit difficult.*

She further described how she felt that she would be holding her friends back when they went out and that they would not understand, so instead '*I'll just go on my own or just go with somebody who's got a special needs child, I mean that was easier, and that was the easy option'*. Jayne similarly described how '*friends who haven't got children with special needs have definitely empathised, they were really kind, but I don't think they can fully understand it'* and Clare discussed how she could not talk to her friends about the tribunal she was going through:

> *you feel so overwhelmed. And you can't just reach out and talk to your friends about it, because they don't understand it's so convoluted to start from, you know, square one and explain the whole thing, it would just take days. So quite often, you just sort of go [breathes in] I am really stressed but can't talk about it.*

Connor & Berman (2019:932) suggest that 'the stigma of not belonging with other members of the community impacts the whole family, as if they were 'contaminated' by association'. Similarly, Scorgie (2015:38) also describes how disability can become the 'family identity, a condition'. As a result, mothers of disabled children might question whether they are part of the school community or whether they are also sitting outside of those who are seen to belong in that space (Swart et al., 2004).

Bajwa-Patel & Devecchi (2014:118) argue that parents 'deciding which school is "right" for a child is more complex than a simple placement-based dichotomy between specialist provision and "inclusion"'. Clare described a sense of being '*caught in the middle'* where mainstream schools '*aren't cut out'* for pupils who have Down syndrome meaning that opting for a specialist placement '*seems to be the only option isn't it? Best of, best of the worst? Which is crap really'*. Indeed, many parents face the 'dilemma featuring a special school that does not quite fit or a mainstream school that does not quite fit and may not even agree to offer their child a place' (Bajwa-Patel & Devecchi, 2014:133). Indeed, it can feel like the school that mothers think would be a best fit for their child simply does not exist (Bajwa-Patel & Devecchi, 2014). Emily described how she did not think mainstream would be suitable for Ethan:

> *I can clearly see how unaspirational our local special schools are. They are no more than daycare centre's babysitting children until adulthood. They don't do English or Maths. They stop the children reading as soon as they arrive. They are dead end pathways to social care*.

There is a possible disparity between Emily's hopes for Ethan and the options available to her.

The mothers in this inquiry frequently faced ambiguity and uncertainty when it comes to the decisions that they needed to make about their child's education setting. For example, Jayne described concern about '*token inclusion'* where a child is just '*plonked*' in a school, and it is called inclusion. When we first met, she was preparing for Zebedee to start school. With a sense of humour Jayne described how she dropped Zebedee off for a tennis course in the school he was due to attend:

> *they've built this new like enclosure with a fence around. And I was like, oh gosh is that for Zebedee? so he can't run away. I really hope that's not for Zebedee, that they have made this pen for him.*

Although she had chosen a mainstream school for him, she was still concerned that he would be physically set apart from his peers. When we met just a later after Zebedee had started school, she described how, in preparation for our meeting, she had written a note that stated that *'the inclusive environment sometimes that does mean times of different or "exclusion" and being separate, set apart and that's okay if the overarching ethos is one of inclusion'.* She further described how:

> *there are times when Zebedee is at school where he is taken out, he is he does go and do speech language. Or here or there or he'll fall asleep and I will go to collect them and they will say he's asleep on the beanbag and that's not actually happening so much anymore. But I was like, that's okay, like it's okay if he is taken out the class and it has been a bit disruptive. Or that's okay if everyone's general kind of attitude is we want to include him.*

This was a shift from where we first met. Jayne now felt that for Zebedee to be included in the school it was also necessary to exclude him at times. Scorgie (2015:37) suggests that 'when children are labelled 'different' or 'other,' their place of belonging within the general classroom can also be questioned'. She introduces the term 'ambiguous belonging' to describe 'parent perceptions that they and their children are not accorded full, equal membership within the school community' (Scorgie, 2015:36). There is an ambiguity about what inclusion looks like for Zebedee, which Jayne is now having to engage with.

Wright (2015) states it is important to understand how 'belonging' is being deployed, due to its multiple meanings and uses. She argues that 'what is most important about the term is the texture of how it is felt, used, practiced and lived' as well as there being a need 'to attend deeply to the ways belonging is constituted by and through emotional attachments' (Wright 2015:392). In the section above, I have drawn on previous research and the conversations with mothers in this inquiry to discuss the close conceptual relationship between inclusion and belonging. I have demonstrated that when the notion of successful inclusion is conceived as needing to feel a sense of belonging, mothers of those who do not 'fit' with the normative expectations and standards may start to think that mainstream education is not suitable and that maybe a separate specialist setting would be better for their child as they would be happier and less isolated. If, however, taken for granted understandings of belonging are questioned, and alternatives are presented, this can enable a shift in thinking away from which children do or do not 'fit' within mainstream education, instead recognising that inclusion and belonging are continually becoming, meaning that the spaces and relationships within them are open to ongoing change.

11.4 Affective non-belonging

As mentioned previously, belonging can be conceived and experienced in multiple ways. Wright (2015:391-2) suggests it is 'at once a feeling, a sense and a set of practices' and that it is important to engage with 'performances of belonging, and to the ways belonging is actively created through the practices of a wide range of human and more-than-human agents, including animals, places, emotions, things and flows'. Rather than suggesting that it is the individual child who does not belong, I now shift to thinking about belonging as relational and constitutive. Belonging is not a benign term, rather it is imbued with powerful exclusionary logics despite currently being deployed within a rhetoric of inclusion. When disabled children are considered within 'normalising discourses of "age-appropriate developmental milestones", expected academic performance, and behavioural patterns' it becomes possible to suggest that some pupils just do not belong in mainstream education (Connor & Berman, 2019:924). Their inability to belong in this environment constitutes them as ‘misfits’ who would be better off educated together somewhere else (Lalvani, 2013). Misfits do not pre-exist. Rather, as Wright (2015:393) discusses, ‘belongings are made’ as things, people and places come together, and therefore ‘belonging can be seen as an act of becoming’. In this section, I discuss this further to argue that when inclusion and belonging are seen as two sides of the same coin this can result in the separate education of disabled children being sought.

When we discuss belonging as ‘being accepted by others, of fitting into existing social organisations, including schools and local communities’ (Connor & Berman, 2019:932), it also draws attention to those who do not belong, for instance the ‘people, practices, objects, germs and performances that are, somehow, not meant to be in a place’ (Wright 2015:395). Wright (2015:395) explains how the ‘opposite of belonging may be exclusion; it may also be isolation, alienation, loneliness, dis-placement, uprootedness, disconnection, disenfranchisement or marginalization’. One of the concerns frequently raised by mothers in this inquiry, as discussed above, was the worry that their child would be isolated within a mainstream education setting. As Lalvani (2013:436) explains, ‘students with developmental and intellectual disabilities are at risk for social isolation, and compared to students without disabilities, have fewer reciprocal friendships, a lower rate of social participation in inclusive learning environments, and tend to be relegated to the periphery of the classroom community’. The mothers in this doctoral inquiry were also acutely aware of this and it appeared to be a significant influence when they were discussing which type of setting might be most suitable for their child.

The affiliation to a place, for instance a school, can often be understood as having an emotional nature to it. As Wright (2015:399) explains, it is ‘the emotion, the sense of belonging, that helps create the distinction of what is on the inside, what is the same, and what is on the outside, and therefore different – that which does not belong’. It is therefore important to consider the role of emotions when exploring how the notion of belonging might result in the exclusion of disabled children from mainstream education. No mother wants to see their child isolated or without meaningful relationships. Clearly emotions ‘do things’ (Ahmed, cited in Wright, 2015:398). Navigating friendships and ‘managing her position in the school community’ can be anxiety inducing and stressful for mothers of disabled children (Connor & Berman, 2019:932). There is a significant practical and emotional labour that goes into trying to find a sense of community, a space for your child to belong (Connor & Berman, 2019), which can be exhausting and isolating for the mother too. As Anne described in our conversations, ‘*I think the thing that kind of came through to me was that actually if I, if I want James to be included in this, then it's me that’s got to do the leg work… but you know, I’m tired’.* Often the responsibility for fitting in and belonging is placed at the feet of the disabled pupil and their parents (Robinson & Notara, 2015). Clare described how, when thinking about what it would be like if Thomas were to go to a mainstream secondary school, which would have been her preference:

> *He won’t be included… the worry is that because there's no expertise in the school that I will be so involved with his education. Every year, everything will change. I'll have to reinvent the wheel. And I found that exhausting, you know… it's making my heart sink’*

further adding '*So do I want to reinvent the wheel every bloody year. No I do not'.* The emotional and physical impact felt by the mother can be more powerful as an exclusionary mechanism than 'formal exclusion' techniques such as exclusions for challenging behaviour[84].

It is important to recognise how belonging is continually becoming, as it is 'performed in messy, negotiated and material ways' that have an impact (Wright, 2015:400). As Antonsich (2010:652) describes, it is not 'a primordial, essential feature that people have'. Rather multiple belongings – and non-belongings – are constructed and co-constituted in relation to a range of human and non-human entities. A sense of not belonging can come to the fore when your child is never mentioned or celebrated in the school newsletters, where the same newsletters portray disabled children as objects of pity when discussing Children in Need or other fundraising appeals, where your child's work is never displayed within school corridors, where they fail to secure a role in the school play and are sat at the back banging a drum, when you notice that other children do not want to play with your child any more or refuse to invite them to their birthday party, or when you are stood alone in the playground at school pick up time every single day. Parents of non-disabled children can be unwilling to invite children labelled with SEND to their home or for a sleepover (de Boer et al., 2010).

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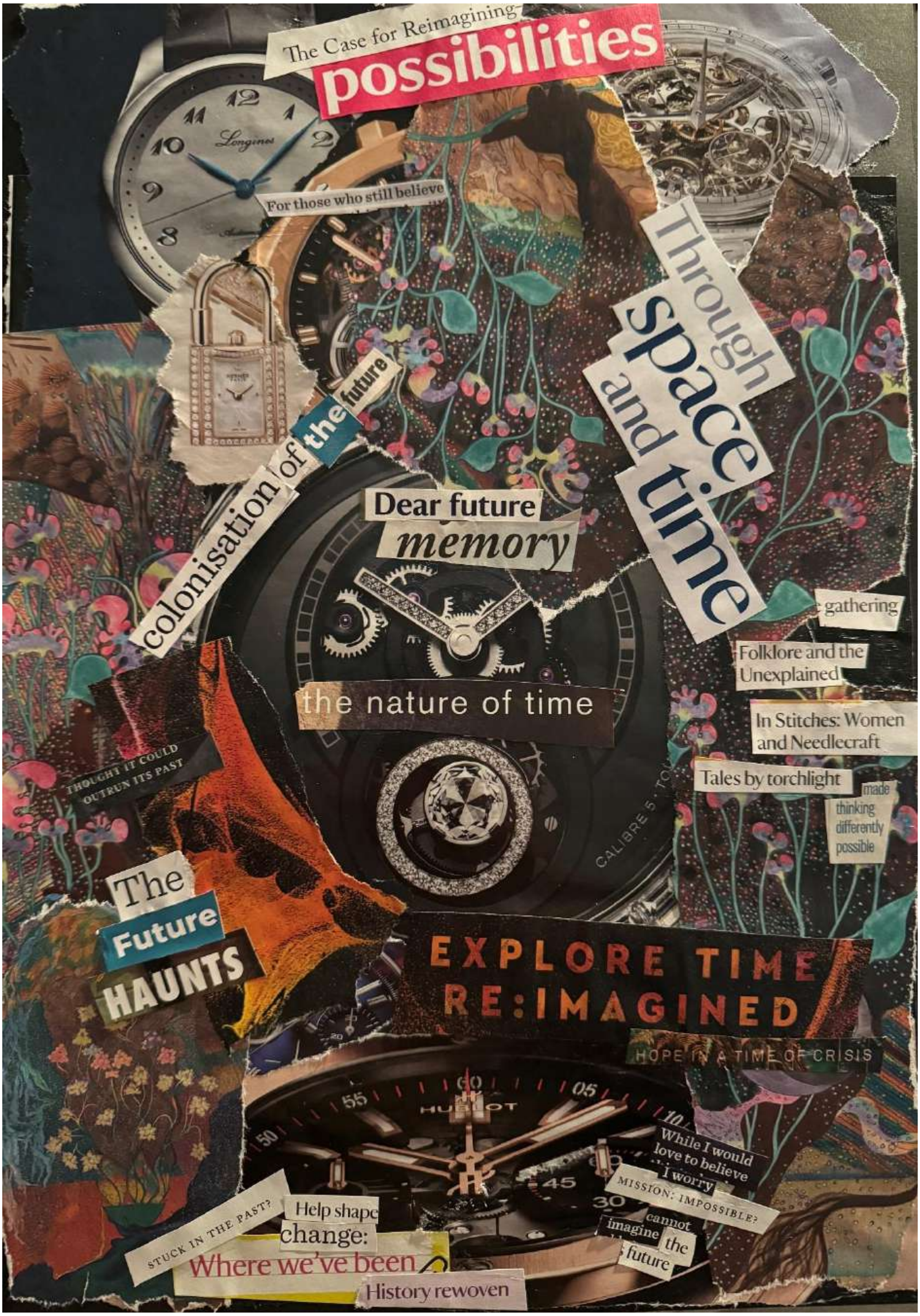
[84] I discussed exhaustion in Chapter Nine also.

These everyday encounters and feelings of their child being excluded matter, and they have an impact on mothers. For example, Clare described having to manage her own disappointment and sadness about Thomas not being included:

> *I spend a lot of the time just suppressing my own feelings about things. Yeah, pushing it down and pushing it out pushing it down. And you know, I will just burst into tears at the traffic lights.*

It is therefore important to recognise how the day-to-day experiences of non-belonging can be 'experienced in intensely personal and emotional ways' (Wright, 2015:399). These scenarios are 'painfully real' and tell parents that 'their children do not belong' (Slee, 2019:916). It is necessary attention to these experiences and feelings, and the sense of exclusion that they produce.

These 'minor' yet affective encounters can also shape what mothers of disabled children think is best for their child. Parents are subsequently seen to 'choose' specialist provision, because their child cannot 'fit' into mainstream education, rather than there being any recognition of the contributory factors that have led to this situation. Slee suggests that mothers 'having been buffeted around by acts of exclusion will seek refuge through home schooling or at the special school and paradoxically their decisions will be described as exercises in choice' (Slee, 2019:916). As Tsalapatanis (2019:23) describes, 'feelings of not belonging, or of having one's belonging contested may not come about through the obvious instances of exclusion, but rather through the build-up of minor encounters'. To feel a 'sense of belonging', the idea that you are part of a 'we' not a 'them', it is important to feel that you are part of the community, that you are 'at home' (Antonsich, 2010:648). If this sense of 'place-belongingness' (Antonsich, 2010:648) is not felt, then it feels a reasonable response for mothers to try to find it elsewhere. Further, as discussed above, sometimes it is just the anticipation or risk of not-belonging or fitting in that will suggest to a mother that maybe her child should be educated in a specialist setting.


The Case for Reimagining
possibilities
For those who still believe
Through space and time
colonisation of the future
Dear future
memory
gathering
Folklore and the Unexplained
In Stitches: Women and Needlecraft
Tales by torchlight
made thinking differently possible
the nature of time
THOUGHT IT COULD OUTRUN ITS PAST
The Future HAUNTS
EXPLORE TIME RE:IMAGINED
HOPE IN A TIME OF CRISIS
While I would love to believe
I worry
MISSION: IMPOSSIBLE?
cannot imagine the future
STUCK IN THE PAST?
Help shape change:
Where we've been
History rewoven

11.5 The Temporality of Belonging and the Haunting of Not Belonging

When my daughter was in infant school, parents of older children who have Down syndrome warned me that we would find inclusion significantly harder in junior school. They suggested that it would be almost impossible for her to stay in mainstream junior school past Year 5, because that is when children who have Down syndrome move to special school. Once she reached Year 6 in mainstream junior school, the same parents encouraged me to choose specialist provision for secondary school, arguing that she would not cope in a big mainstream school and that there would be a lack of therapy due to LA blanket policies. Future challenges and the possibility of her future exclusion came to the fore. I describe this experience because it is important to understand how 'ideas about the future play in people's sense of belonging' (May, 2019:75). For example, Jayne described how the choice of mainstream school for Zebedee was influenced by her desire for him to be able to '*survive in the big wide world'* after his education finished, adding:

> *How are children… if everyone with special needs is put in a separate school? How are they then… they get to the end of school and what are they supposed to do, all stay together? Like go live in a home together or? If it doesn't start now, when are you ever gonna …. And that's what's important for us. I think just like, this is his life. This is how he's going to live his life.*

Sita similarly described that the most important thing for Kiran was to learn so that he could '*go out into the world, into the future adult world'.* It is clear that the future is often 'an integral dimension of belonging' (May, 2019:77). As May (2019:76) discusses, 'past experiences and future plans' interact with each other in the present, in a continual negotiation of what it means to belong. Therefore, it becomes important to consider '"past futures" (the future as it was anticipated in the past), "present futures" (the future as it is seen now) and the present' (May, 2019:76) when considering what it means for disabled children to belong in education.

In one of our conversations, Clare described how she grew up with '*complete segregation'* and '*kids on the special bus',* in comparison to children today who are growing up watching Mr Tumble on CBeebies[85]. Clare recognised that she is '*just seeing everything through the lens of the 1980s'* when she imagines what Thomas's future education might look like. She was especially concerned about him moving to a mainstream, describing how:

> *when I imagined it in my mind's eye. I'm imagining people bullying him. I cannot imagine the positive side of it at all.*

Clare further described however that she did not want to '*limit him'* with her own fears. Here we can see the intra-action of the different temporalities – past, present and future.

May (2019:85) describes how when we 'pay attention to how people talk about the future, we can see belonging in the making – or as it may be, in the unmaking'. Based on her experiences of education in the 1980s, Clare imagines a future in secondary school where Thomas is excluded and bullied. As de Boer et al. (2010) describe, parents who have had more experience themselves with inclusive education are more positive about what the inclusion of children labelled with SEND. Clare's experience of the exclusion of disabled children in education in her past, combined with every day ordinary affective encounters with ongoing exclusion, such as Thomas's diminishing invitations to birthday parties,

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[85] Mr Tumble is a cheery character on a BBC children's TV programme 'Something Special'. He uses Makaton sign language to communicate. The character is played by Justin Fletcher who also appears in the show as himself, talking to disabled children. My daughter appeared in the show with her best friend when she was 6 years old, baking biscuits with Justin.

potentially limit her ability to imagine a future where he is happy and included in a mainstream secondary school.

The future can be seen as ‘haunted’ and mothers of disabled children can be seen to ‘exist in a state of haunted motherhood: they are paralysed in anticipation of an imagined future’ (Morriss, 2018:816). As Gordon (2008:xvi) describes, haunting ‘alters the experience of being in time, the way we separate the past, the present, and the future’. The past exclusions of disabled children live with us today, and shape what mothers of disabled children think is possible. The vivid memories and imagery of children being sent on the ‘special bus’ remain, ghosts of past exclusions that mean a future of inclusion is unimaginable. The absence and invisibility of disabled pupils succeeding in mainstream education continues to haunt the present and the future. As such, this ghost ‘has a real presence’, producing ‘disturbed feelings’ that cannot be put away (Gordon, 2008:xvi).

As I have described above, unlike traditional haunting about the past in the present, this haunting is ‘also a matter of the future’ (Morriss, 2018:822). The past haunts imagined visualisations of the future, where the exclusions of the past shape future possibilities (Morriss, 2018). Barad (2017:84) suggests that memory ‘is not merely a subjective capacity of the human mind’ rather it is part of the ‘spacetimemattering of the world’. A mattering that shapes the ‘conditions of possibility’ and ‘what matters’ (Barad, 2017:80). The fear of future exclusion becomes real, and it has an impact on the decisions that mothers make about where their child will be able to fit or belong.

Unfortunately, as previously described in Chapter Ten, the inclusion of children labelled with SEND is not guaranteed but is conditional on being able to fit in with the normative requirements of the setting[86]. This 'conditionality' of inclusion can lead parents to feel an increased sense of vulnerability, which can obstruct any feelings of belonging (Vandenbussche & de Schauwer, 2018:976-7). Such conditionality was experienced by Sita when she wanted Kiran to attend the school's breakfast club. She described how she was told '*we're going to give him a trial'* where if he could not neatly fit in, he would have to go home. Sita further describes:

> *when I dropped him off on the first day of school I did, like, I cried, you know, so you know all this anxious, like oh my goodness is he going to cope as he went in the Breakfast Club.*

This conditional inclusion is stressful for mothers as they experience an anticipation, a sense of waiting for their child to be excluded. Vandenbussche & de Schauwer (2018:874) describe how many parents will face 'uncertainty about the future' and about how their child might 'participate and belong' when inclusion is conditional. However, they further assert, 'uncertainty is the starting point to question the things we do and how we do them' and it challenges us 'to think about who we are when we belong and where' (Vandenbussche & de Schauwer, 2018:975).

Anne described how she felt the need to embrace uncertainty, offering an alternative perspective to thinking about the future. She described the need to avoid anything that might '*colonise the future'* for her son James. Instead, she described needing to be comfortable with '*dealing with the uncertain',* to '*expect the unexpected'* and to avoid

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[86] This was also clearly evident during COVID-19 when schools failed to provide additional learning materials or lessons for many pupils labelled with SEND, instead sending Twinkl worksheets or no schoolwork at all.

thinking '*too far ahead'.* She described how James needed to find his own way and to '*enjoy the moment*', meaning that she needed to be comfortable with the fact that you cannot possibly know the future as '*who knows where it's going to go'*. She described how '*James is great for that as he just lives in the moment, hurrah!'.* She described how she sometimes reflects on the past and might regret decisions that she made, but also how she did not know then what she knows now. She suggests that with the benefit of hindsight she might have made other decisions about James's school placement, however she also does not want to spend too much time thinking about this because she made the best decisions that she could have done at the time with the information that she had.

Gordon describes how ghosts 'hate new things precisely because once the conditions that call them up and keep them alive have been removed, their reason for being and their power to haunt are severely restricted' (Gordon 2008:xix). Instead of seeking to control or 'colonise' the future, based on her imagination of what she thinks might be possible, Anne is allowing James to make his own future belongings and she is stopping her past decisions from having haunting power over her. Morriss (2018:826) describes how it is important to reclaim 'the living present and the possibilities of potential futures' which can enable movement and change. A sense of belonging or non-belonging is not only 'situated in the "now"' (Gabi, 2013:43) but is also affected by previous experiences, even if those experiences are the experiences of others. As Deleuze describes, 'the past does not follow the present that it is no longer, it coexists with the present it was' (Deleuze, 1989:79). The past and the present reconstitute each other. Belonging unfolds in layers, different stories being painted of past, present and future, in perpetual motion (Gabi, 2013).

As mentioned earlier, stories abound within parent support groups about exclusions and the challenges of mainstream education for disabled children. Emily described:

> *I've watched their stories and watch them fighting. I've watched them say their children regress, loads of them. I've watched them say, you know, their children have got no friends. Why would I follow them*?

George describes how '*when you're under the category of Special Needs Mums… you tend to listen more to the views of everyone'*, further describing how there will always be '*stories going round'* about schools that would influence the decisions made. Even though these events that inspired what could be seen as '"folkloric" knowings' (Massumi, 2002:215), having occurred in a different time and place, they take on a life of their own, almost becoming legendary as they are passed on between mothers who are unsure of what decision they should make for their own child's education.

Stories about previous exclusions tell us who should and should not belong in mainstream education. George explained '*I didn't discuss with any with anyone whether or not Ezra would go mainstream. I just knew in myself'*, before discussing how she didn't know anyone from their Down Syndrome support group who had gone on to mainstream secondary school. She further explained that specialist education for secondary is '*just the norm of what I have heard… the journey that you are supposed to do'.* She described how '*yeah I have probably always thought, yeah SEN school for secondary'*. Emily similarly described how even when Ethan was young, she '*just had this feeling, that he'll end up in special school'.* Stories that are passed from generation to generation of mothers are a haunting, as the ghosts of exclusion influence the decisions that mothers might make for their child's education in the present. The ghosts of exclusion have never gone away, they live within our education system, alive and well within discussions of belonging and inclusion. Instead of thinking these ghosts are dead and long forgotten, it is necessary to recognise their continued haunting. As Barad (2017) describes, we have a ‘relationship with and responsibility to the dead, to the ghosts of the past and the future’ (Barad, 2017:86). Hauntings, such as those I have discussed above are ‘not mere recollections or reverberations of what was. They continue to be alive, to affect, to bring about future exclusions. Hauntings are an integral part of existing material conditions’ (Barad, 2017:74) and it is therefore necessary to recognise how they can influence mothers and how they think about their child’s belonging.

When we face these ghosts head on and recognise what they are ‘alerting us to’ (Morriss, 2018), ie. the exclusion inherent within our current education system, then it becomes possible to tell alternative stories of alternative futures and belongings. As Massumi, describes, it is ‘only by leaving history to reenter the immanence of the field of potential that change can occur’ (Massumi, 2002:77). When we grapple with the ghosts that haunt us and bring them to the fore in the stories we tell, it becomes possible to hear the warnings that they bring whilst also creating new stories of future uncertain belongings.

11.6 Misfitting

As discussed previously, this thesis draws on feminist materialist theories that emphasise relationality, materiality and affective encounters when thinking about meaning-making and subjectivity as becoming. These theories recognise phenomena as being produced through ‘entangled and shifting forms of agency’ (Garland-Thomson, 2011:592). Garland-Thomson (2011:592) explains how, instead of conceiving disability oppression as emanating from ‘prejudicial attitudes’ that manifest in ‘architectural barriers, exclusionary institutions and the unequal distribution and access to resources’, she offers the idea of ‘misfitting’, which considers instead the co-constituting relationship between the body and the environment in different situated encounters. As she explains, the individual ‘in a misfit materializes not in herself but rather literally up against the thingness of the world’ (Garland-Thomson, 2011:594).

The space in which disabled children and their parents navigate their lives – including their education – tends to ‘fit’ majority bodies and functioning, and therefore creates ‘misfits’, those who develop an ‘outcast status’ (Garland-Thomson, 2011:594)[87]. They are seen to belong elsewhere. This can be seen, for example in Dunne’s discussions of inclusion with educationalists, whereby inclusion was seen as ‘a fundamental good’ but ‘not for everyone’ (Dunne, 2008:49). As Dunne (2008:52) explains, every time ‘difference is named, made visible, or created, for example by professionalised and technicised talk of ‘the ‘SEN’ child; the ‘included’ child… the ‘vulnerable’ child; or the child ‘suffering from’ low self-esteem, the invisibility and the power of a fictionalised normativity, and of hegemony, is strengthened and secured’. Those who sit outside the ‘circle’ of belonging, whose needs are seen as too difficult, or who are seen as lacking in some way, are produced as students who could not be included (Dunne, 2008:49-50).

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[87] See also Chapter Nine where I discuss misfitting in relation to disability activist affordances

As I describe above, the ‘primary negative effect of misfitting is exclusion from the public sphere’ (Garland-Thomson, 2011:594), which can include being educated in a separate setting to other children who can ‘fit’ within the demands of mainstream education settings. Whether a body fits or misfits in a space determines whether an individual can join in and participate in shared activities. If there is a good fit, this produces a ‘material anonymity’ where an individual is ‘unmarked’ and does not ‘stand out, make a scene, or disrupt through countering expectations’ (Garland-Thomson, 2011:596), whereas those whose bodies struggle to share the same material world will find their right to belong is under threat. In a classroom, a pupil who has Down syndrome might find that the chair is slightly too large for their frame, meaning that their feet do not touch the floor causing instability, they might struggle to see the fine lines printed in their workbooks that they are meant to write between, or they might not be able to understand or retain the complex written instructions presented to them on a worksheet with text that is far too small for their vision impairment. Alternatively, they might need visual resources to help them understand concepts such as time or conditionality, that are not provided, or they might need longer to process and answer questions than the time allowed by the teacher, never putting their hand up in time to be asked for their ideas to be shared in the classroom. Between their body and the material education environment there is a misfitting. This is not the child who is the misfit, as suggested by the mother in Lalvani’s research (Lalvani, 2013), rather it is a situation of ‘misfitting’ whereby the particularity of the child’s lived embodiment and the environment come together in ‘disjunction’ (Garland-Thomson, 2011:592). Should the material, spatial or temporal context shift, fitting might occur. Misfitting is therefore not a stable situation, but it does, as I have explained above, have significant material affects whereby some children are produced as ‘misfits’ who are seen to belong elsewhere, which has real-life consequences (Garland-Thomson, 2011:593).

To address this situation, Garland-Thomson (2011:597) suggests it is necessary to ‘speak directly to the issue of reshaping body and world’. She is not suggesting that individuals should reshape their bodies so that they can fit better, rather to recognise misfitting as having ‘political potential’ from the production of ‘subjugated knowledges from which an oppositional consciousness and politicized identity might arise’ (Garland-Thomson, 2011:597). She suggests that it is important to ‘expose the relational component and the fragility of fitting’ (Garland-Thomson, 2011:597), as I am doing within this inquiry. However, I would argue this is more complex when those who are constructed as misfits are cognitively disabled. Garland-Thomson’s examples of the misfitting between bodies and environments discuss individuals who have physical impairments rather than cognitive impairments, for example wheelchair users who cannot access a building or someone with a visual impairment attempting to use a voiceless ATM machine. Garland-Thomson suggests that ‘much of the disability rights movement grew from solidarity born of misfitting’ (2011:597), however as discussed previously[88] and by McKearney & Zogas (2021:111), the social model of disability and disability activism both have an ‘overwhelming focus on bodily disability, one which echoes a wider neglect of mental forms of disablement in academia and society at large’. Therefore, it is possible to argue that those who are cognitively disabled might be seen as misfitting with the disability movement itself, for instance if they do not have the cognitive abilities to engage directly in activism. This is not to say that misfitting is not a

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[88] See Chapter Two

useful concept to help build the argument presented in this chapter, rather it is necessary to point out its potential limitations for those whose bodies include cognitive as well as physical impairments.

Recognising this limitation of Garland-Thomson's work, McKearney & Zogas (2021:211) argue that it is necessary to pay 'attention to the dynamic fit between the *particular* way in which a given person's mind works and the everyday relational processes in which cultural expectations are worked out' (original emphasis). Therefore, when considering the theoretical application of misfitting in relation to education, it is necessary to recognise that it is not only a pupil's body but also their cognitive capacities where there can be a misfit with the expectations and demands of the education setting.

As a mother, I have regularly had to witness and experience my daughter's misfitting, her rejection by others. When meeting the SENCO at our local catchment school, where our son already attended, we were told in no uncertain terms that the teachers at the school would be unable to differentiate to a low enough level for our daughter, and nor could they be expected to produce a timetable that she could understand, instead we would need to do the adaptation. We were told it was our choice if we still wanted to send her there, which we inferred to mean that the responsibility for any future problems or exclusion would be ours rather than the school's. Our daughter did not fit within the imagined pupil who would and should attend that school. The mothers who took part in the conversations in this inquiry have also experienced similar, for instance being told that schools cannot meet their son's needs or being the only parent needing to closely supervise their son in a football activity. Indeed, such everyday encounters of misfitting are familiar to many mothers of disabled children (Robertson, 2014). However, it is through these often painful and challenging experiences that misfitting mothers can become more attuned to 'the extent to which certain environments cause misfit and disablement' (Robertson, 2014:unpaginated). As such this can become a 'productive' experience, as mothers gain unique knowledges and 'innovative perspectives' that can lead to social change (Robertson, 2014:unpaginated)[89]. As Robertson (2014:unpaginated) describes, it becomes possible to 'embrace our misfitting and use it for good in the world'. Thinking with ideas related to misfitting can allow us to think differently about what it might mean to belong.

11.7 A shift in thinking about belonging – becoming more Beth!

When considering inclusion within education, it is often conceived as whether a disabled child can fit into an existing mainstream setting with appropriate adaptations, leaving the setting unchanged. Graham & Slee (2008:278) argue that such 'cosmetic adjustments' within mainstream education 'simply work to (re)secure an invisible centre from which constructions of Otherness and the designation of marginal positions becomes possible'. It is assumed that there are 'typically-developing' or 'normal' pupils who belong within mainstream education and those who need to demonstrate and prove their ability to belong there. There is a suggestion, therefore, that disabled children are brought into a pre-existing space and included by those who are already there, those who naturally belong there (Graham & Slee, 2008). Accordingly, as discussed above, this leads mothers of disabled

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[89] This links to the argument I presented in Chapter Ten about affordances and mothers being readers of power.

children to question whether their child might belong or whether their belonging in the space of mainstream education will be too difficult or painful for them. Graham & Slee (2008) argue that it is necessary to banish idealisations of the illusory and ghostly normative centre[90], which produces the minority Other. Slee (2019:911) suggests that what is needed is a move to thinking about 'belonging as an educational aspiration in an attempt to imagine the conditions of education where belonging is authenticated by practice and not simply a rhetorical flourish or tactical distraction'. Yet, as I have described above, commonplace understandings of what it means to belong can lead to the further exclusion of disabled children. Hence why it is necessary for us to think differently about what it means to belong.

Instead of thinking about individuals or spaces as already-constituted, my aim here is to think about belonging as emerging in-relation. As Massumi (2002:71) describes, individuals and the spaces that they live – or are educated in – are 'not only empirically inseparable, they are strictly simultaneous and consubstantial'. He expands further to explain how 'they might be seen as differential emergences from a shared realm of relationality that is one with becoming-and belonging' (Massumi, 2002:71). Accordingly, this requires a shift in thinking, to redefine and reconfigure understandings of what it means to belong, recognising that there is a becoming emerging from an array of events and affects that will contribute to different ways of belonging. For Massumi, affect becomes 'the connecting thread of experience', an 'invisible glue' that shapes our belonging in the world (Massumi, 2002:217). Belonging can be conceived as 'fluid as opposed to being fixed', a 'phenomenon that is constantly shifting' which encourages us to 'shift from a binary oppositional perspective to

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[90] Another haunting…

nomadic thinking' (Gabi, 2013:258-9). When belonging is seen as constantly evolving – as becoming - it is necessary to recognise how individuals are constantly having to navigate 'the sometimes treacherous terrain of membership' within groups or spaces (Gabi, 2013:41).

I am reminded here of Ulmer's writing about wildflowers, where she suggests that 'communities might be planted, gardened and cultivated according to the same principles that enable wildflowers to thrive' (Ulmer, 2020:784). Wildflowers are weeds, plants that are seen 'as undesirable, lesser plants' (Ulmer, 2020:783). Weeds should be eradicated, removed from gardens as they are 'not cultivated enough for our aesthetic (or productivist) sensibilities' (Kruger, 2021:732). However, they are also beautiful and often eye-catching, as well as being resilient, often found to be thriving in hostile landscapes such as cracks in pavements or alongside busy roads. Ulmer describes how we can take a philosophical stance whereby we stand in solidarity with the 'plants someone did not think were good enough to be in the garden' (Ulmer, 2020:783). Drawing on her discussions of wildflowers, Ulmer suggests that we should seek 'spontaneous cultivations of difference' rather than seeking assimilation, recognising that we live in a world where we depend on others (Ulmer, 2020:785). Rather than attempting to eradicate the wildflowers, it becomes necessary to 'cultivate inclusive and desirable practices as we hold onto the warm and vibrant spirit of community gardening' which is undertaken together (Ulmer, 2020:786).

Drawing on the idea of dwelling with wildflowers, Kruger suggests that this '*togetherness…* implies a willingness to let go of the illusion that privileges thinking and knowing (mind) as an individual endeavor and repositions it within the relational processes of life-living'

(Kruger, 2021:734, original emphasis). We should recognise our ‘relationality and mutual coexistence’ and embrace our ‘*togetherness* with the world’, which can grow ‘from radical openness and attentiveness to one’s environment’ (Kruger, 2021:734, original emphasis). Irigaray & Marder suggest that we need to allow ‘our natural belonging flower’ (cited in Ulmer, 2020:787). This is an orientation where we look both at ourselves and our environment to envision new actions that we can take to shape the world we live in. As Ulmer (2020:787) describes, wildflowers ‘might encourage different paths’ helping us craft the kinds of futures that we want for tomorrow, ‘finding a way, together’.

Bodies can find themselves ‘at odds with the built environment’ in everyday activities, whether this is doorways, furniture or a lectern that is the wrong height (Hendren, 2020:3-5). The world is built for the ‘normal, average body or mind’, a norm that is taken as a ‘reference for the population’, which shapes what is understood as both a natural and right way of being (Hendren, 2020:10-11). Accordingly, disability is produced when the ‘brittle and scripted sense of what a body does or does not do, how it moves and organizes its world’ encounters ‘the shape of the world’ (Hendren, 2020:14). Accordingly, as Hendren (2020) describes, disabled people need greater collaboration to imagine worlds differently, people working together to expand the spaces and worlds we live, work and are educated within, to ensure that everyone’s body and mind can fit. This is not just a case of making adaptations or interventions for one person but is a demand for us to recognise our relationality and the importance of finding a way to produce different paths together.


In a wild meadow by the sea,
Dear future memory makers
CREATE YOUR HAPPY PLACE
dwellings that are focused as much on the walls as on what's growing beyond them.
The House Is a Garden; the Garden Is a House
Inside Out
Rethink
inclusion
From adventure to adventure...
risky positions.
rich in nature,
CLAMBER ON A BUS
MOTION
Deconstructing
ATTITUDES
MAKING TRACKS
LIFE LOOKS DIFFERENT FROM
THE DECK OF A BUS
GET ON BOARD
TO EVOLVE OUTSIDE
Welcome to roam
JOURNEY
PEOPLE AND PLACES
bringing together
people who are discovering
imagine
open them up for more people
WE ARE CONNECTED
WE ARE MOLECULAR
communities coming together
they play a role together, rather than in isolated silos.

During this PhD inquiry, my friend Julia kindly gifted me a copy of *Riding the Bus with My Sister* (Simon, 2002). This book tells the story of Beth, a woman who has an intellectual disability who spends her days riding the buses in Pennsylvania. She has built her own community amongst the bus drivers and other regular riders, as she maps out the city and navigates it in a way that works for her. She invites her sister Rachel, the author of the book, to join her riding the buses for a year, to give her an insight to her life. Although initially dismissive, Rachel soon comes to see the valuable life that Beth has created for herself, and the importance of relationships. Towards the end of the story, she reflects how:

> Maybe we are all Beths, boarding other people's life journeys, or letting them hop aboard ours. For a while we ride together. A few minutes, a few miles. Companions on the road, sharing our air and our view, our feet swaying to the same beat. Then you get off at your stop, or I get off at mine. Unless we decide to stay on longer together. (Simon, 2002:292).

I started to wonder how this could apply to belonging in education. Where we see the space as more transient, as more welcoming of difference and different journeys. Where we need to be attentive to those around us and the environments that we both make and pass through, building a sense of community as we go, becoming more Beth.

11.8 Nomadic belongings

As discussed above, inclusion often centres around an illusory centre, where some pupils are necessarily on the outside. This can lead to discussions about who does, and who does not belong, or which spaces are suitable for specific individuals. It is important to note that, as Probyn (1996:8) states 'if you have to think about belonging, perhaps you are already outside'. For those who are accepted as belonging, there is no need to be concerned about what it means to belong. Probyn, citing Foucault suggests that the ‘spaces in which we seek belonging… “are not a kind of void, inside of which we could place individuals and things”’ (Probyn, 1996:10). Instead, multiple spaces exist, within which there are different modes of belonging determined by both the materiality of forms and the relations within them (Probyn, 1996). It is the materiality and the relations that produce belongings or not belongings. Moving beyond the notions of fixed identity categories, it is important to engage with belonging in more fluid terms, thinking beyond a normative project that determines who does and does not belong in specific spaces. This requires us to move beyond identity to a post-identitarian ‘nomadic’ approach (Braidotti & Strom, 2018:xx).

When we consider mothers and disabled pupils as nomadic subjects, subjectivity shifts from identity categories to ‘a matter of forces, of relations, of capacities, of inclinations… a relational, transversal threshold of interconnections’ rather than a bound entity (Braidotti & Strom, 2018:xx). We are ‘never just one’ (Braidotti & Strom, 2018:xx), instead as Deleuze & Guattari describe ‘[s]ince each of us was several, there was already quite a crowd’ (Deleuze & Guattari, 1987:3). There is a need to move to the point ‘where it is no longer of any importance whether one says I’ (Deleuze & Guattari, 1987:3), where we recognise how we are all produced as multiplicities in connection with other multiplicities, which affect and are affected by each other. ‘Nomad thought’ moves freely ‘in an element of exteriority… it rides difference’ (Massumi, 1987:xii). Stable objectivity, in contrast, is legislated by conformity, ‘universal’ truth and ‘rocklike identity’ (Massumi, 1987:viii). Nomadic space is an open space, it is not limited by preset paths, instead it allows us to ‘break away from the beaten paths’ (Massumi, 1987:xiii). It is a way of living. It is how Beth lives her life. Just as she mapped out the city to make it work for her, Deleuze and Guattari suggest that we need to 'make a map instead of a tracing' (Deleuze & Guattari, 1987:24). Make roots, grow offshoots, be multiple (Deleuze & Guattari, 1987).

Becoming nomad results in shifting boundaries, because of the multiplicities and relations that exist and move within the space. Rather than a fixed normative centre, to which all must aspire, Deleuze & Guattari describe how 'waves or flows of deterritorialization go from the central layer to the periphery, then from the new center to the new periphery, falling back to the old center and launching forth to the new' (Deleuze & Guattari, 1987:53). As McLaughlin & Goodley (2008) describe, mothers of disabled children can be seen as nomadic, as they challenge normative and normalising practices and discourses, immersing themselves in 'more uncertain, open and loving places' embracing an unknown future (McLaughlin & Goodley, 2008:327). We see this in Anne's example previously described, where she refuses to 'colonise' her son James's future, not wanting to limit what is possible for him by her own fears or imagination. Mothers also come together to support each other, as discussed in Chapter Ten where Clare and other mothers took collective action to secure suitable speech therapy provision for their children. Their subjectivity as mothers emerges through 'a socially mediated process of relations and negotiations with multiple others and with multilayered social structures' (Braidotti, 2011:4) rather than through static categorisations that attempt to pin down who they are.

Therefore, instead of seeing some pupils as inferior compared to the norm and excluded or subject to 'interventions' because of their differences, it is important to reconceptualise ‘impaired bodies-and-minds as always in process, always in becoming and in relation to the collective’ (Roets & Braidotti, 2012:165). This ‘collective life is an engine for an affirmative becoming’ within spaces that are no longer seen as firmly bounded but are open and unlimited (Roets & Braidotti, 2012:166). We need to consider belonging as a concept as something that is created, where we engage in political spaces that are always in flux and without fixed boundaries (Roets & Braidotti, 2012). When we reconsider belonging from this angle this provides the opportunity to rethink the inclusion of disabled children who are often posited as belonging outside of mainstream education settings.

The ‘outside’ can often be seen as both ‘a site of oppression’ and a site of exclusion, but also as a ‘liberatory space’ (Probyn, 1996:137). The outside is ‘a production’ and ‘far from inevitable’ (Probyn, 1996:135). As such it becomes possible to flatten the ‘spatial arrangement of inside/out’ (Probyn, 1996:138). Instead of disabled pupils needing to prove their ability to belong, they and their mothers – through productive misfitting – can challenge what it means to belong in the first place. Like Beth, they might make their own maps of the space, and engage in it in a way that recognises them in their continual becoming. This does not mean embracing an ‘outsider’ identity, rather it might involve embracing an ‘outside belonging’ as suggested by Probyn (1996). Probyn describes how we do not live our lives in ‘zones of possible forms of belonging’, that is as ‘general categories’, instead we always ‘spill over the boundaries of the category’ (Probyn, 1996:22). As such, our belonging in specific spaces should not be predicated on the categories we are put into, such as the labelling of a pupil as having SEND. Outside belongings are ‘already *beyond* belonging and identity’, they are a ‘manner of being’ in a particular space, that recognises the ‘impossibility of ever really and truly belonging’ because everything is in motion and becoming (Probyn, 1996:8, original emphasis). They recognise that differences are not ‘absolute’ but that we continually move between categories and spaces (Probyn, 1996:9).

Accordingly, it is necessary to cut the lines that are inherent to dominant notions of identity and instead render incomprehensible the idea that some people do not belong (Probyn, 1996). This requires us to recognise how belongings ‘refuse to stand still’ and that belonging ‘is formulated in neither exclusionary nor inclusionary terms but in its sheer perplexity and yearning bypasses the meanness of individualized identities’ (Probyn, 1996:35). Instead of thinking about fitting in, Probyn (1996:42) suggests that we need to think about the journey, about modes of becoming, and recognising the desire or longing to be a productive force. We need to be attentive to the ‘small movements of belonging… lines of connection and communication between beings, ways of being, and things’. When we become alert to the ‘relations all around us’ we can already start to see strands of emerging relations of belonging, amongst glimpses of alternative ways of being (Probyn, 1996:81). Although Probyn was not writing specifically about education or disability, her work illuminates the importance of paying attention to how disabled children and their parents create new ways and spaces of belonging in education, including through everyday activist affordances as discussed in Chapter Nine. As Braidotti describes, these ‘different becomings are lines cutting open [spaces] and demanding from us constant remapping’ and ‘new coordinates’ from which we align ourselves (Braidotti, 2011:31). As Beth mapped out the city on the buses, she constructed a space that allowed her becoming in relation to others also inhabiting that space. She did not want to be limited by the care package that professionals and her family thought would be appropriate for her, limiting where she could belong.

Deleuze & Guattari (1987:12) describe how a map has multiple entryways and it is:

> open and connectable in all of its dimensions; it is detachable, reversible, susceptible to constant modification. It can be torn, reversed, adapted to any kind of mounting, reworked by an individual, group, or social formation. It can be drawn on a wall, conceived of as a work of art, constructed as a political action or as a meditation.

When we shift to thinking about belonging as fluid and transitory, given its close conceptual relationship with inclusion, this requires a conception of inclusion that is more fluid and transitory. As Deleuze & Guattari (1987:36) also describe:

> The distinction to be made is not at all between exterior and interior, which are always relative, changing, and reversible, but between different types of multiplicities that coexist, interpenetrate, and change places— machines, cogs, motors, and elements that are set in motion at a given moment, forming an assemblage productive of statements: "I love you" (or whatever).

This means it becomes necessary to map out the spaces where individuals are coming together, to identify the 'webs of power, knowledge and social relations' (Roets & Braidotti, 2012:175) that are constituting inclusion and exclusion, belonging and not belonging. Attention particularly needs to be paid to the boundary making practices that exclude, through which we are reminded that 'things could always be otherwise if this assemblage was composed and performed in a different way' (Giraud, 2019:172). By making exclusions visible, it shifts the focus from individual children to finding ways to 'foster accountability' and 'create space' for relations 'to be contested in the future' (Giraud, 2019:75). Although not writing specifically about SEND, Giraud (2019) suggests that to realise responsibility for exclusion and find ways to respond to complexity, it is necessary to ‘go beyond an ethics oriented around proximal relations and encounters’ and to pay attention to longer histories. In this thread I have discussed both and have also demonstrated how the past and present come together to shape imagined future exclusions which are felt as real by mothers of disabled children and potentially lead to the choice of specialist education settings. I have, also presented an alternative vision that recognises everyone as becoming and sees misfitting as productive, as a starting point for change.

There is a risk that discussions of nomadism are seen as a ‘romantic projection’ by the intellectual elite that is distanced from the oppressed groups being discussed (Pels, 1999:76). Pels (1999:77) suggests it can lead to a form of ‘nomadic narcissism’ that denies the realities and challenges faced, as it instead offers a form of escape. This is not my intention here, as I know only too well these challenges as I live and breathe them every day. Instead, my intention is to introduce a new way of thinking about belonging, as something that is not entailing a disabled child to prove that they can fit into a pre-existing educational space. Rather to think about what it might mean if we think about what it means to belong in different and more nomadic ways. This is not to romanticise a nomadic life. As discussed above and in Chapter Nine, it is exhausting to be a mother of a disabled child who is attempting to effect change, to expand the space in which her child is welcomed. Instead, my intention here is to open new fields of inquiry into the relationship between inclusion and belonging, to challenge taken for granted conceptions of what is means to belong, and to question the conceptual relationship and ontological underpinnings of both.


ISLANDS OF ADVENTURE
THINK
GO YOUR OWN WAY
Grey sky thinking
MAKING TRACKS
If we don't get lost we'll never find a new route
RAINY DAYS DON'T HAVE TO BE A WASHOUT.
KNITTING TOGETHER
LET YOURSELF BE GUIDED
"Be less guided by the grids of the map, and more by a particular purpose..."
DORCHESTER'S FAMOUS GHOST WALK
THURSDAYS
STARTS 8 pm
KINGS ARMS HOTEL
ADULTS £6
CHILDREN £3
WALK THE PAST
NURTURE
NESTING SPOTS
FILLED WITH WHATEVER LIFE BRINGS
from the
OTHERWORLDLY PLACE
Until everyone has a home and nobody lives in a cage.
"I CAN'T APPLY COLOUR THEORY LIKE A 19TH-CENTURY PAINTER, MY GUT GUIDES ME"
LET THE DAY YAWN
STOP, READ AND WONDER
"The deep focus you need to build and hone an idea comes from the 'slow mind'. Time alone is crucial to allow ourselves space"
forging strong relationships
"Perhaps it's a desire to create space for human connection in a time when so many of us are isolated, and carrying our stories alone"
"Our way of doing things is quite organic: we just kind of gather things together and let it evolve"
Immersion
Early evening and the water is at its warmest. There are three options: tentative paddling, excited splashing or the full plunge.
A WORD ABOUT EARTHWORMS...

12. (NON)CONCLUSIONS AND BECOMINGS

12.1 Weaving the threads together

The threads presented in this thesis are just three possibilities within a multiplicity that could have emerged from this inquiry. The use of rhizomatic conversations as a form of research generates infinite possibilities about how the inquiry could be cut-together-apart (Barad, 2014) and presented, which means that I must take responsibility for the ‘agential cuts’ (Barad, 2014:168) made within this thesis. It is important that these cuts do not result in the foreclosure of other possibilities. Tentacular, unfurling in multiple directions, the threads are designed to create openings to keep the conversations in motion, rather than perpetuating stagnation. The threads are partial, tentative, uncertain, probing. They are a writing in process, ‘marking the space between theory and empirical work without precise boundaries’ (Hanley, 2019:415). Whilst the three threads were presented as separate, and potentially discrete, there are clear overlaps and crossovers between them. The presentation of the emerging threads as different chapters within this thesis should not suggest neat delineations. Each thread may stand alone, but each is also entangled in their co-becoming. The space in-between offers a further ‘possibility space’ (Hanley, 2019:420) where each reader of this thesis can make their own connections and will each take different things from their engagement with the thesis and the ideas within it.

As previously discussed, academic research has suggested that some parents desire inclusive education in relation to securing their child’s human rights and belonging in wider society, whereas others may choose specialist provision because it offers a ‘safe haven’ and a sense of belonging with others who were like them. Further, research suggests that parental characteristics, such as level of education or occupation (Leyser & Kirk, 2004) or social-class (Bagley & Woods, 1998), or the influence of advice from professionals or friends (Byrne, 2013) leads to parents making a particular choice about the type of education that their child receives. These previous studies present parents as rational, autonomous individuals who are presented with a ‘choice’ or at least the ‘illusion’ of a choice between mainstream education and specialist settings. However, the threads emerging in this thesis suggest and illuminate a more complex picture, one where both disabled children and their mothers are constantly having to navigate ‘the sometimes treacherous terrain of membership’ (Gabi, 2013:41) within several groups or spaces within education settings. This approach shifts the focus to a necessary recognition of the multiple ‘frictions, foreclosures, and exclusions that play a constitutive role in the composition of lived reality’ (Giraud, 2019:3) of mothers within a hostile education system for disabled children, which sometimes only the most tenacious and well-supported can navigate.

This inquiry has demonstrated that mothers of disabled children are subject to increasingly pervasive discourses that position them as being part of the problem, as being too demanding, too sharp-elbowed, too emotional, or as saboteurs, terrorists or warriors who do not understand the appropriate ways to engage in parent partnership which requires teachers to put appropriate strategies in place to support them to become a different type of parent[91]. They are required to engage in statutory processes that are complex and

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[91] As suggested by the framework presented by Hanna, which was discussed in Chapter Nine.

confusing, where the professional viewpoint is often prioritised, reports are often missing or late, and their own contributions are reduced to feelings. They face everyday exclusions, both explicit and implicit within the school system, such as being turned away by school leaders who state that they ‘cannot meet need’ or a lack of birthday party or playdate invitations, acutely feeling their child’s increasing isolation. At the same time, the ghosts of past, present and future exclusion are haunting. The vivid memories and imagery of seeing disabled children being sent to school on the ‘special bus’ remain, ghosts of past exclusions that mean a future of inclusion becomes unimaginable. Stories of not belonging can start immediately following the birth of a disabled child, as mothers receive numerous copies of ‘Welcome to Holland’ and horror stories of future inevitable exclusion take on a life of their own in support groups and social media forums. Furthermore, knowledges and exclusions are produced through the agentic nature of documentation, where documateriality has an affective quality that produces future exclusion.

The intra-action of statutory processes, power relations with professionals, explicit and implicit experiences of exclusion, the agentic nature of documentation, and the haunting of past, present and future exclusions can be ‘inadvertently shutting down potential ways of becoming’ (Giraud, 2019:73) and limiting what it means to belong in education. These threads demand that we recognise the ‘myriad of world-making relationships’ (Giraud, 2019:5) that mothers engage in, from which exclusionary subject positions, knowledges, materialities and affects can emerge. It is also important to recognise what the relational entanglements ‘do’ and how they impact on what mothers of disabled children think is possible and on the actions that they feel they must take to ensure their child is included in education in a meaningful way.

This inquiry has drawn attention to how mothers of disabled children engage with the narratives, processes, and exclusionary practices within education. Mothers are resisting these through a range of means, such as the use of memes on social media or by collaborating on SEND processes that are designed to focus on one individual. They enact every day, often invisible, affordances to make the education system more hospitable for their child, and they resist notions of '*colonising the future'*[92]. Alternative futures can be imagined when dominant narratives are challenged, when attention is paid to the pain of exclusion faced by disabled children and their mothers, and when the ongoing haunting is recognised and ghosts of past, present and future exclusion are faced head on. The threads highlight the importance of engaging with the 'becoming' of those who are the misfits, the outcasts, the castaways as they contest the 'infrastructural and material-semiotic relations that reproduce and naturalize inequality' (Giraud, 2019:30) and find their own ways of belonging in spaces that are not designed with them in mind. Such an approach to inclusion recognises the necessity to 'become-with each other or not at all' (Haraway, 2016:4).

The threads presented also offer a call-to-action, as they push and pull against each other, urging a reconsideration of how the inclusion of disabled children in education and the role of mothers are conceptualised and how exclusions are experienced. They offer hope that

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[92] As discussed by Anne in Chapter Eleven.

things can and do change and highlight the important role that innovative research can play in creating space for imagining new happenings, becomings and understandings of what it means to belong. I recognise that inquiries that highlight tensions, complexities and entanglements can ‘prove as paralyzing for questions of action and intervention’ (Giraud, 2019:176). Indeed, putting the focus on ‘relationality and coming together’ can make political action harder to realise (Giraud, 2019:4) and this can have the greatest negative impact on those who are most excluded. It is important to me that this inquiry does not make it *more* difficult to think about inclusion, that it does not paralyse. Rather, my hope is that it offers a space to create something new by exploring how particular realities and identities might come into being, to present ways that we can think otherwise, and to ‘explore the possibilities for action amid and despite this complexity’ (Giraud, 2019:2). Once the entanglements and relationality of inclusion and exclusion are brought to the fore, as in this inquiry, it becomes necessary to then consider the necessary actions to be taken and where obligations lie (Giraud, 2019).

12.2 Contributions to knowledge

My own positionality as a mother of a child/young person who has learning disabilities is central to the contribution that this thesis makes, initially in its innovative methodological approach, utilising conversation *as* research with mothers of disabled children, and then the knowledge that emerged from the explicit felting of mothers’ experiences and theory. Despite much attention and discussion over the last five decades, inclusion remains contested and contingent, and families continue to face challenges in securing a meaningful education for their disabled child. Within academic research going back to the 1990s, the same arguments and experiences continue to be rehearsed. Concepts such as belonging appear frequently yet are not explored in any great depth within SEND-related empirical research. If research is to help move the inclusion debate forward, a new approach needs to be taken to ensure that it can say something new or suggest new avenues for exploration, as this inquiry has done.

The methodological approach introduced in this inquiry relies on a relational processual ontology, rather than a traditional humanist approach that is based on Cartesian dualisms. In this way, it makes an explicit shift away from individual agency and identity to a recognition of the subjectivity of mothers of disabled children as becoming, emerging through a process of co-constitution within shifting multiplicities. The inquiry used the innovative approach of conversation *as* research to explore the complexity of mothers' experiences relating to the education of disabled children within a framework of relationality and connectivity, to bring the assemblages within which they are entangled to the fore. Here conversations are not used as data to be analysed, but as important contributions to unsettle and to move on philosophical thinking. As a result of this new methodological approach for research undertaken with mothers of disabled children, the inquiry produced further unique contributions to knowledge that are surfaced within the three threads presented and the creative offerings woven throughout the thesis. These threads might stand alone to introduce new ways of thinking about these topics, highlighting areas that are sometimes overlooked, such as the affect of home-school diaries, to generate moments of hope for the inclusive education of disabled pupils. However, their full contribution exists in their ongoing entanglement, which recognises emergent knowledges as tentative, remaining open-ended and full of possibility in their ongoing becoming.

I have extended Dokumaci's work of disability activist affordances (2017; 2020) into theorising about the education and inclusion of disabled pupils and the role of mothers of disabled children within this. The relational ontology used within this inquiry enabled a shift in thinking about disabled pupils, away from focusing on the individual who is seen as lacking or not fitting into a pre-determined education space, to recognising how both the pupil and the space are constantly becoming and emerging through relation and actions. Likewise, the notion of an isolated mother battling a hostile education system attempting to secure inclusion for their child in a pre-existing education space is shifted to recognising mothers as being constituted in relation. Introducing the idea of activist affordances to theorising about mothers of disabled children, I demonstrate how mothers are engaging in every day, often invisible work, enacting affordances to minimise the extent to which mainstream education shrinks for disabled children. Their actions are an ongoing attempt to make mainstream education more hospitable and inclusive of disabled children, for whom the system was not originally designed.

This contribution to knowledge enables a move away from static and stable representations of mothers of disabled children, for instance as warriors or terrorists, to a recognition of the important role that mothers play in the inclusion of disabled children. The significance of the knowledge of mothers enacting affordances is that it allows education practitioners to understand the relationships and events in their individual settings that produce exclusions or worries about future exclusions and to take action to remove these barriers. When school leaders and educators understand the actions that mothers take as proactive attempts at making the setting more inclusive and hospitable, these actions can potentially be implemented by the setting for the wider school population instead, to ensure the full inclusion of all disabled children.

The second thread explored, and surfaced, the contribution to knowledge of a new concept of documateriality in relation to SEND. This concept defines the interplay of materiality and the affect that SEND documentation can have on mothers of disabled children. The rarely discussed role which the materiality of the accumulated paperwork of education, assessment, and professional reports on parents is revealed, to demonstrate a unique understanding of how documents come to matter and what realities are produced through documentation processes and performances, which can subsequently shape what mothers of disabled children think is possible or desirable in relation to their child's inclusion in education.

I draw on recent work that has explored the agential nature of documentation in Early Childhood Education (Lenz Taguchi, 2010; Murris, 2016; Pettersson, 2019; Albin-Clark, 2021) to extend this generative theorising into the field of SEND. This produced new knowledges about what SEND related documents can and do 'do', and the potential impact they can have on inclusion. Rather than seeing documents, books and images as 'tools of humans' (Kummen, 2014:813), I make the argument that it is important to recognise how SEND documentation as matter *matters*. This contribution to knowledge drew attention to how the materiality of SEND documentation can impact mothers' beliefs about what is possible or desirable for disabled children as well as how both pupils and their mothers can be produced and fixed as subjects through documentation practices. I highlighted the importance of recognising the affective capacity that documentation has and how this affect can constrain capacities for parents who are attempting to secure the inclusion of disabled children in education.

Prior research has explored the experiences of mothers who engage in the EHCP process, yet the discussion of 'documateriality' within this inquiry further extends the area of concern beyond EHCP documentation to everyday practices of documentation such as home-school diaries or the ways in which mothers use documentation as forms of resistance. The significance of this knowledge is that it allows policymakers and educators to pay attention to the documentation practices that they engage in, to understand the agentic power that exists within the materiality of the documents used, from which they can engage with mothers of disabled children to generate more collaborative and inclusive documentation practices that will support the full and ongoing inclusion of disabled children.

The third thread examined one of inclusion's frequent 'conceptual bedfellows' *belonging*. The concepts of inclusion and belonging frequently appear unquestioned as synonymous in discussions about the education of disabled children, where belonging is a 'shadow concept' (Bissell et al., 2019:2) of inclusion. This aspect of the inquiry generated new knowledge about why mothers of pupils who have Down syndrome may be seen to 'choose' a specialist placement for their child despite resisting notions of otherness in all other aspects of their lives. I extended the work of Gordon (2008) about hauntology to explore how mothers' opinions about inclusion are shaped by the past, present and the imagined future. This thread explored how current exclusionary actions are entangled with haunting stories about previous exclusions that tell us who should and should not belong in mainstream education, and how mothers imagine the future. I introduced the important new concept of the Temporality of Belonging and the Haunting of Not Belonging, whereby potential exclusion in the future can be seen to haunt mothers of disabled children as much as past or current exclusions do. These ghosts of past, present and future exclusion have never been exorcised. They continue to haunt our education system meaning that it is necessary to recognise their haunting and then find ways to remove their power to exclude.

This theoretical contribution to knowledge suggests the need for opportunities within both research and practice, where mothers are given the tools and strategies from which they can imagine different futures, to confront and exorcise these ghosts. This might include an exploration of what it might mean to belong in different and more nomadic ways, based on a recognition inclusion as becoming, emerging from an array of events and affects that will contribute to different ways of belonging. The significance of the knowledge emerging from this thread is that what it means to belong needs to be negotiated by everyone within the space and it should not be assumed that everyone has the same understandings of belonging. By paying attention to the contributions of those who do not easily 'fit' or 'belong' in existing spaces, action can be taken to imagine different kinds of belonging and inclusion that will allow for the full inclusion of disabled children in education. This is not a one-off exercise, but is a continual process of becoming more inclusive, recognising the multiplicity of structural, material and affective factors that can contribute to a sense of not belonging.

This inquiry recognised the complexity and entanglements that contribute to the inclusion of disabled children, providing alternative knowledges to those presented in existing research studies. The (non)conclusions of this thesis and its generative methodological approach suggest a multiplicity of ways to take this work forward and implications of the knowledges that emerged. Importantly, this inquiry has demonstrated that bringing together real-world knowledges, relational philosophies and theoretical perspectives can generate new avenues to explore inclusion in ways that purely empirical or philosophical inquiry might fail to do. This has implications for the work that philosophers of education engage in, where they draw on poststructural or posthuman theories, recognising the importance of recognising the multiplicity of human and non-human entities that can inform and direct philosophical inquiry. It also has implications for those engaging in empirical work relating to inclusion, demonstrating the importance of inclusive philosophies to shape the inquiry in a way that will generate new knowledges that embrace complexity and in-depth explorations of often taken-for-granted concepts being utilised.

Finally, the contributions discussed were produced from a research inquiry that took place during a well-documented ‘SEND crisis’ in England and were further impacted on by the global COVID-19 pandemic. These additional pressures and the recording of their impact within this thesis also forms a unique record of this time.

12.3 Implications for education policy and practice

As previously discussed, the notion of ‘parent partnership’ was introduced in the 1978 Warnock Report (DES, 1978). This concept has subsequently evolved from parents being required to support interventions and learning at home, to being seen as ‘experts’ who can engage in strategic ‘co-production’ of SEND services. The Government’s current SEND & Alternative Provision Improvement Plan (HM Government, 2023) suggests that parents should be involved ‘as equal partners’ in developing National Standards, a ‘nationally consistent EHCP process’ and standardized EHCP templates (HM Government, 2023:37). The aim of partnership is to ‘maintain positive relationships locally’ to ensure that families can ‘engage constructively’, which should ‘prevent issues from escalating’ (HM Government, 2023:76). However, neither of these approaches provides the space for the types of conversations that need to take place, as suggested by the findings of this inquiry. Instead of seeing parents as resources or equal partners, it is necessary to create opportunities where questions are asked about how everyday exclusions and processes of marginalisation come into being, how they are sustained, and ‘to ask whether things could be otherwise’ (Giraud, 2019:32). These discussions can only take place with those who bear the brunt of the exclusions, primarily mothers of disabled children and, of course, their children, due to their unique critical perspective on what needs to change for them to be included in mainstream education.

There is currently no space for emotion in meetings with professionals when advocating for one’s own child, or when engaged in strategic co-production. ‘Mum’ must act professionally, and to argue for changes in provision using evidence, documentation or the legislative framework, as many of the mothers in this inquiry described having to do. Anything else will be dismissed as ‘feelings’ that are emotion-based and irrational. However, as this inquiry has demonstrated, to surface the multiplicity of exclusionary events, or processes, that mothers of disabled children experience, attention must be paid to affective and emotional encounters, and what these *do*, to expose relations of power and exclusion that come to matter. Indeed, as Giraud (2019:180) suggests, it is ‘necessary to (critically) recuperate practices that are ordinarily sidelined from conceptual consideration (such as rights or emotional responses that are often sidelined for being overly sentimental)’. It is only through this exposure that possibilities for meaningful inclusion can emerge.

This requires an urgent and radical rethinking of ‘parent partnership’ and ‘co-production’. As Giraud (2019:178) explains, ‘sometimes it might seem like space is being created for certain actors to impose their obligations, or for transformative expressions of agency and resistance to manifest themselves, when these possibilities have already been rendered impossible through prior encounters and inequalities’. Current conceptions of co-production may give the illusion that mothers are having the opportunity to shape SEND services and provision at a strategic level, however, the space being provided to do this is still within the existing constraints of SEND legislation, the wider education context and ongoing exclusionary policy and practices. Instead, those involved in seeking solutions to inclusive education need to have the space and ‘the resources required to articulate the complexity of an issue’ rather than being restricted to co-production as the required ‘mode of political articulation’, which can ‘foreclose alternative perspectives while leaving the status quo untouched’ (Giraud, 2019:43). Instead of mothers of disabled children being used as resources to support their child’s education, their experiences of exclusions and not-belonging can be generative and productive in *rethinking* what educational spaces must look like if they are to include everyone. However, the material arrangements underpinning partnership and co-production provides only one conception for collective knowledge production, foreclosing other options that recognise the value of the emotional and affective work engaged in by mothers of disabled children.

Disabled children and their mothers are already attempting to reshape what it means to belong in mainstream education, through enacting disability activist affordances and new ways of belonging. Educators need to stop categorising mothers and devising suitable strategies for dealing with them, and instead should create opportunities to pay attention to the mothers’ performances through which these activist affordances emerge and to discuss why mothers feel these actions are needed. Recognition of these affordances as being a response to ‘mis-fitting’ will highlight where changes need to be made for a child to be meaningfully included. As Hendren (2020) argues, we need to make assistance visible, and make it a matter of wider interest than just the individual for whom assistance is being provided. When attention is paid to the affordances and actions that mothers are taking, the everyday exclusions of their children become more visible, from which it also becomes possible to foster accountability and recognise who is responsible for effecting change. It becomes clearer which processes and actions are impacting on what mothers feel is possible within mainstream education for their child and the choices they subsequently make.

The EHCP process, which also has its origins in the 1978 Warnock Report (DES, 1978), introduced statutory assessments and Statements of Special Educational Needs, focusses on the 'needs' of one individual and the adaptations or interventions that they might need. Sometimes these needs are seen as too great or the provisions as too specialist or expensive for a child to be able to belong within mainstream education. However, this thesis has demonstrated that knowledges and realities are created about pupils within entangled relationships between both the human and non-human entities, for instance the affect of documateriality, and how 'it is vital to pay attention to the tools that are entangled with this production of knowledge' (Giraud, 2019:46).

Rather than standardising the EHCP process and documentation, consideration should be given to thinking about how the statutory assessment process could be otherwise. Currently the views and perspectives of 'mum' are summarised in the one short section of the EHCP and are not seen as having the same level of importance as the professionals' reports which set out needs and provision required. This could be imagined differently, for instance collaborative reports could be produced and the starting point of ascertaining what support and resources are required could be agreed at a setting level rather than for an individual child, with an annual review of what the school needs to become more inclusive based on the input of those who are now inhabiting that educational space. This inquiry does not purport to provide the answers for alternative approaches to inclusion, it does not present evidence of 'what works'. Rather it requires, as Hendren (2020:206) describes, people coming together in a collective 'for a moment around a possibility or an idea' that might have been 'newly augmented by crisis' but perhaps was there all along. It demands collective action that recognises our entangled relationality and the importance of creating opportunities for everyone in the education system to contest existing boundaries, and instead to forge pathways and desire lines (Hendren, 2020:143) that will produce new maps and ways of engaging in spaces where we can all become and belong together.

12.4 Feedback provided to the Department for Education (DfE)

At the beginning of 2022 I was invited to present my research as ‘work in progress’ to the Department for Education (DfE) in an online webinar. This was an incredible opportunity, and my immediate instinct was to go straight to the mothers who took part in this inquiry to invite them to suggest what they felt the important key messages coming out of our conversations were. I asked each of them to each provide me with up to three key messages that they wanted the DfE to hear, ideally generated from our conversations. Some sent me short responses, others sent incredibly detailed replies. I shared the draft presentation with them for their feedback and further contribution before presenting. The slides discussing the outputs of the inquiry included quotes from within our conversations. The mothers communicated that they valued the opportunity to shape the key messages being presented to policy makers, and that it was also an affective experience. After reading the draft presentation, Emily emailed to say:

> *It was really emotional reading because I was kicking myself wondering why I hadn’t said everything that everyone else had said. Each quote spoke for me too…and quite possibly for us all?*

The key messages that were presented to the DfE were:

- There is not a ‘one-size fits all’ approach to inclusion;
- Practitioners who have a ‘can-do’ attitude frequently have prior experience or relationships with disabled people;
- Inclusion is all about relationships and having a can-do attitude;
- There needs to be greater accountability and training of local authorities and professionals feeding into the SEND process;
- The curriculum needs to have greater flexibility built in;
- Friendships and relationships need supporting;
- The impact of engaging in the system on parents (especially mothers) and the whole family needs to be considered.

This inquiry gave mothers of disabled children a unique opportunity to reflect on their experiences of the education system, and to generate their feedback that was presented directly to those working in policymaking roles at the DfE.

12.5 Implications for ‘inclusive’ research with mothers of disabled children

At the beginning of this thesis, I discussed my aim to design a research approach that is inclusive, whilst also recognising that there are many understandings about what it means to be inclusive. As researchers, we have an ethical obligation to ensure our research about inclusion considers what knowledges and realities are produced in research encounters and related documentation through the boundary-making practices that make and exclude worlds (Hollin et al., 2017). It is necessary to understand ‘what is excluded from particular entanglements' and the agential cuts that researchers make (Hollin et al, 2017:936). As Giraud (2019:68) explains, to effect change, 'it is a matter not just of creating space for others to speak and be heard, but of actively working to overcome and oppose affective relations that shore up existing oppressions'. As Barad (2007:19) describes, 'there is something fundamental about the nature of measurement interactions such that, given a particular measuring apparatus, certain properties *become determinate*, while others are specifically excluded' (original emphasis). It is necessary to understand 'how different differences get made, what gets excluded, and how those exclusions matter' (Barad, 2007:30). The decisions we make within research, the apparatus that we use, can therefore shape what knowledges are produced and whether these knowledges perpetuate or contest exclusion and oppression. As researchers, we bear the responsibility of working with those who experience those exclusions, to shape our research in a way that is meaningful for them. As a mother of a disabled young person, I was able to bring my experiences into every aspect of the planning and implementation of this inquiry.

As well as using philosophies that are not based on humanist based ideals of what it means to be human, I drew on Nind's discussion about inclusive research with people with learning disabilities to help think about what it means to be inclusive in research. Nind (2017:279) describes how the term 'inclusive research' originally pertained to 'doing research with people with learning disabilities', therefore I will be using the terms 'undertaking research inclusively' or an 'inclusive approach' throughout this discussion because this is not an inquiry that is being undertaken with people who are learning-disabled. Although I did not undertake research with learning-disabled people, it was possible to incorporate many of the tenets or values of inclusive research she suggests within this inquiry. Nind provided questions for reflection about those who want to undertake research 'inclusively and well' (Nind, 2017:285-6), which I adapted for use with mothers of disabled children. I set out these adapted questions below, together with examples of how this was achieved within this doctoral inquiry:

Nind's questions	My adapted questions	Within this inquiry
Is the topic relevant to the lives of people with learning disabilities and interesting to them? Could it become relevant?	Is the topic relevant to the lives of mothers of children with learning disabilities and interesting to them? Could it become relevant?	Each time we spoke, the research conversations started with topics/objects of the mothers' choosing. Many of the conversations were about the mothers' real life experiences and the challenges or opportunities they were embracing. Our conversations were meaningful to them. The ongoing conversations over a 12 month period provided the opportunity to return to topics to provide clarification or to explore them in greater depth if they wanted to.
Does the research involve people with learning disabilities	Does the research involve mothers of children with learning disabilities	The research was designed as conversation to recognise the everyday nature of conversations that take place between mothers of disabled children. The aim was

in a meaningful and active way?	in a meaningful and active way?	to recognise the value and importance of maternal knowledge throughout. Meetings were set up at a time and place that was most suitable for the mothers involved in the inquiry, with reminders sent that explained it was perfectly understandable if the meeting needed to be rescheduled. Transcripts were sent and the option for any amends or redactions was provided. The draft thesis was also sent to all of them to see and comment prior to submission. This allowed all participants the opportunity to provide input on the final thesis.
Are the participants in the research treated with respect?	Are the participants in the research and their children with learning disabilities both treated with respect?	During the inquiry, I maintained contact with the mothers, providing updates and timescales for the next stages. On occasion, my personal life meant that some of these timescales needed to shift, but I contacted them immediately to explain why and to apologise. I was respectful of differing views throughout, and the method of conversation was used to embrace and welcome discussion about topics that might be difficult to talk about with others.

Is the research communicated in a way people with learning disabilities can understand and respond to?	Is the research communicated in a way people with learning disabilities can understand and respond to? Is the research communicated in a way that mothers of disabled children can understand and respond to?	I have produced an Easy Read version of the thesis, with the specific aim of communicating details of the inquiry with learning-disabled people. I attended training with PhotoSymbols to provide me with the necessary skills to do this. I have attempted to make this thesis accessible, even though it draws on complex theories in places. Whilst writing the thesis, I had the mothers engaged in this inquiry in mind throughout, knowing that I would be sending it to them to read in draft form and after submission.
Is there honesty and transparency about everyone's role and contribution?	Is there honesty and transparency about everyone's role and contribution?	I clearly explained to the mothers taking part in the inquiry that this was not a traditional research inquiry before they took part. I explained that the conversations were not designed to produce 'data' for analysis, but that the conversations would be a catalyst for theorising about inclusion and mothering. I have checked that they are happy with how their words have been used in this thesis and in presentations or other representations of this research, eg a blog post for Twinkl SEND.

Were the ways of working carefully thought through and adapted in response to needs?	Were the ways of working carefully thought through and adapted in response to needs?	I was careful in the original consent form, instead producing a shared agreement to demonstrate my commitment to the mothers engaged in the inquiry. All meeting times and locations were agreed in advance. Towards the end of the inquiry, Faith asked to send email text rather than meet, as she found this easier than speaking (due to English not being her first language) so we communicated that way. Prior to every telephone call or meeting I would send an email reminder, in which I reminded the mothers that we could postpone if needed. One mother asked me to send her a text message an hour before a Zoom call, which I did. For future research, I would not make any assumptions in advance about what participants' preferences might be regarding pseudonyms and would instead build in opportunities to discuss the tensions and implications of using pseudonyms, allowing participants to make an informed decision.
Does the research create worthwhile knowledge?	Does the research create worthwhile knowledge?	The conversations led to new avenues of thought in relation to the inclusion of disabled children in education.

Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?	Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?	As I will shortly discuss, the mothers reported finding the conversations useful and therapeutic. They valued having the opportunity to talk to someone who was not a close friend but who would empathise and who had enough knowledge that they did not have to explain things in great detail. One mother (Faith) felt that the inquiry gave her strength to continue her quest to secure a more inclusive education for her son, as she knew she was not alone.
Are the research questions the kind that inclusive research can best answer?	Are the research questions the kind that inclusive research can best answer?	This inquiry is underpinned by inclusive philosophies that value difference and recognise the entangled nature of subjectivity. The use of conversation was also to ensure that the inquiry was flexible for mothers, in terms of both being shaped around their interests and also in practical terms. These two factors led to the creation of a research inquiry that led to new knowledges being produced that answered the research questions. The emergent meaning-making recognised tensions, complexity and movement in a way that more traditional methods might not achieve.

Does the research reach participants, communities and knowledge that other research could not reach?	Does the research reach participants, communities and knowledge that other research could not reach?	There is a plethora of research that engages with mothers of disabled children. However, the approach taken in this inquiry has helped generate new knowledges that have not emerged from previous research, eg. the affect of documateriality, or considering mothers of disabled children as enacting disability affordances on behalf of their children, as I discuss in Chapters Nine to Eleven.
Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?	Does the research use, and reflect on, the insider cultural knowledge of parents of children with learning disabilities?	This is at the core of this inquiry. Not only were the conversations valuing the mothers' perspectives and interests, but my own experiences as a mother of a disabled child helped shape the design and implementation of the inquiry too.
Is the research genuine and meaningful?	Is the research genuine and meaningful?	There has been genuine and meaningful relationships throughout the inquiry, some of which have continued after the formal research period finished. I also approached the inquiry with a genuine curiosity and desire to improve the education of disabled children, because of I want to help improve the education system for children and young people who are disabled like my daughter.

Will the research make impact that people with learning disabilities value?	Will the research make impact that people with learning disabilities and their families value?	I am committed to ensuring that it does. I have already used some of the conversations with the mothers to help shape an information campaign for the Down's Syndrome Association, producing new resources and running a series of events. This work continues into 2024. I have also contributed to blogs and online magazines/forums too, as well as delivering guest lectures to trainee teachers and SENCOs.

Conversation proved to be a suitable approach to undertaking research with mothers of disabled children. Utilising conversation as inquiry enabled new knowledges to emerge that avoided any representation of mothers of disabled children. Instead, the use of conversation enabled an approach that recognised a 'becoming-together', resisting any notion of 'individual-bodied-ness and of bodies with boundaries' (Zarabadi et al., 2019:91). Instead of generating texts about personal experiences that would be 'interpreted', conversation enabled a form of knowledge production that recognises 'material connectivity' within processual relations (Zarabadi et al., 2019:91). Mothers of disabled children – and I as researcher – are no longer recognised according to attributes or categorisations, as a Cartesian human who can be compared to another, but instead entangled knowledges emerged in multiplicity, in assemblage, in an expansive movement through and beyond the conversations that took place (Zarabadi et al., 2019). This method has been generative in creating new knowledges, and it has provided an innovative and inclusive approach to research inquiry with mothers of disabled children.

It is important to recognise that whilst conversation was found to be a highly suitable approach to undertaking an inquiry with mothers of disabled children, multiple other methods could have been designed as an alternative approach. Whilst the use of conversation as research worked well within this inquiry, which was designed by combining my experiences as a mother/research participant and the philosophical perspectives that I was working with, and indeed it could be replicated as a method by others, my aim was not replicability. Instead, what was important was designing or choosing an approach that:

- was underpinned by inclusive philosophies;
- allowed for complexity and new knowledges to emerge rhizomatically;
- recognised mothers of disabled children in their becoming, resisting any urge to stabilise or fix them within bounded categories or representations.

Conversation as inquiry met all these requirements and was therefore suitable for the questions that I wanted to explore within this inquiry.

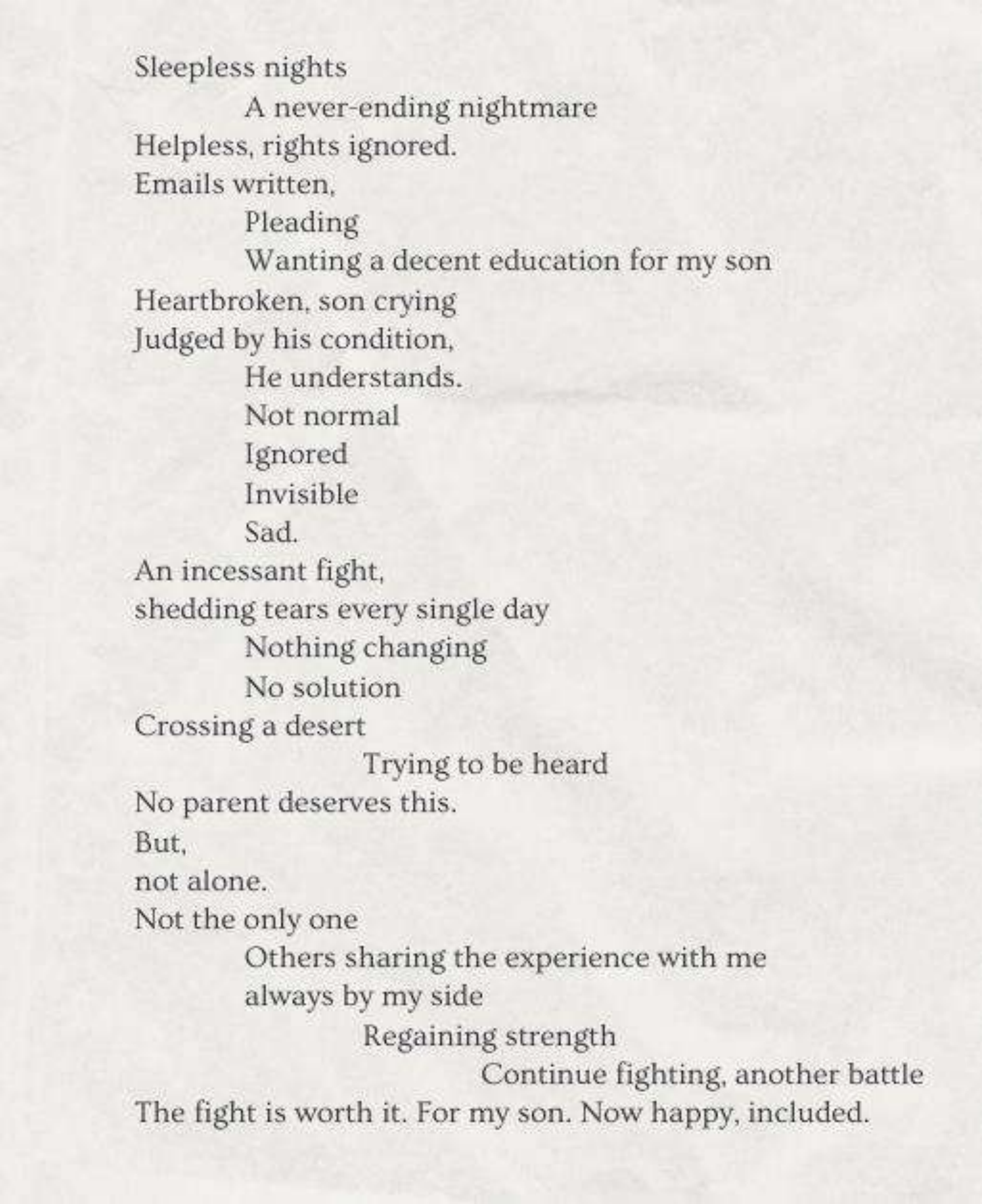
As discussed previously, I came to creative research approaches in the latter stages of this inquiry, when considering analysis and dissemination. It can see how it would have been beneficial to incorporate some of these activities into the research inquiry/conversations with mothers of disabled children, so that the inquiry was not only based on their words but also maybe through other forms of conversation, eg. collage or poetry as I utilised once the conversations had ended. This approach has been seen in other inquiry, for instance both Safron (2019) and Kuby et al. (2022) used scrapbooking with pupils to explore identity and subjectivity. In both projects, the pupils undertook scrapbooking as a collaborative activity within the classroom, with ideas sparking off each other, generating new possibilities and potentialities from their relations and entangled subjectivities. Kuby et al. (2022:291) suggest that this research-creation approach offers a ‘boingy space’ in which subjectivities can be made and unmade, through a focus on ‘relational becomings with materials and each other’. Safron describes using collage alongside conversation to create assemblages through the affective materiality of the scrapbooking process (Safron, 2019:47). This would be something exciting to consider for future research with parents of disabled children, who might find the activity both generative and therapeutic, as they further explore their identity and subjectivity with and through materials as I have done (even if they, like me, might initially find it daunting). This would also potentially overcome some of the language challenges that Faith experienced, as someone who did not have English as a first language. This is a project I would be keen to pursue in the future.

12.6 Future research directions

The nature of this inquiry has opened multiple avenues for future inquiry. I am interested in engaging further with the concepts of Temporality of Belonging and the Haunting of Not Belonging. I believe that it would be fruitful to incorporate creative research methods into an inquiry with mothers of disabled children to imagine different futurities and approaches to inclusion. I would also be interested in further exploring the affective nature of documateriality, to gain further insights into the role that the physical presence of documents in the family home can have and what affects these produce. It would be particularly timely for this to include an exploration of the impact of digital documentation given that the current SEND proposals include a move to both standardise and digitise EHCPs.

The outputs from this inquiry also suggest that further research could also be undertaken to explore the everyday affordances that mothers of disabled children make to help the hostile education system become more hospitable for their child, particularly to consider how and when mothers engage in everyday forms of collective action, such as collaborating on tribunal submissions. Further, with collective action in mind, it would be generative to inquire further into how mothers of disabled children use social media platforms, for instance the production and circulation of memes and what these creative objects that have a virtual materiality ‘do’.

These are just some of the opportunities for future research arising from this inquiry. As readers engage with this thesis and bring it into relation with their own interests and priorities, hopefully a multiplicity of options will emerge from the threads and creative outputs produced in this inquiry.



Sleepless nights
A never-ending nightmare
Helpless, rights ignored.
Emails written,
Pleading
Wanting a decent education for my son
Heartbroken, son crying
Judged by his condition,
He understands.
Not normal
Ignored
Invisible
Sad.
An incessant fight,
shedding tears every single day
Nothing changing
No solution
Crossing a desert
Trying to be heard
No parent deserves this.
But,
not alone.
Not the only one
Others sharing the experience with me
always by my side
Regaining strength
Continue fighting, another battle
The fight is worth it. For my son. Now happy, included.

Transcript poem: Having faith

12.7 Participant feedback and reflections on impact

When I started my PhD journey it was because I wanted to make a difference for families who are struggling to navigate the SEND system. So here I pause and ask what difference this research has made.

One of the aspects of undertaking research that I had not really considered before starting this inquiry was the benefits to the parents involved in the inquiry. However, due to the way that the research was designed it led to direct benefits for the mothers who took part, I was able to offer different support, information or resources as I engaged as a mother and researcher within the conversations.

This included:

- Passing on a Numicon kit to Jayne from a Down syndrome support group that was seeking a home for it, to support Zebedee when starting school.
- Providing Sita with links and information about behaviour in children who have Down syndrome from the DSA, when she was going into school to discuss Kiran's behaviour. Sita described to me how it made her feel more confident and that she was taken more seriously when she went to the meeting:

  > *so they knew I was gonna like speak to somebody and and get all the evidence and come to the meeting*' and '*this mum is already behind everything, she knows everything, you know, Because they've been told that I've got somebody like, like, you know who's supporting me*.

- Making a referral to the charity Contact for Faith and providing her with IPSEA templated letters which might help her with her request to move Brave to a more inclusive mainstream school. Faith described: '*the research study help me to inspire me to do more things for my son. Because I feeling I am not alone*'.

- Collating a list of questions to ask about inclusion when visiting potential Secondary schools, following a request from Clare.

Feedback from subjects of research is rarely heard (Shah, 2006). Dennis (2014) describes how 'the actual experiences of participants in the research process are being taken largely for granted', due to little empirical work about research participants' experiences of engaging in qualitative inquiry (Dennis, 2014:397). This generally does not warrant significant attention unless participants have been harmed through their engagement, despite their commitment of both time and energy in studies (Dennis, 2014). Therefore, at the end of the inquiry, I invited each mother to reflect on their experience and asked whether anything could have been improved.

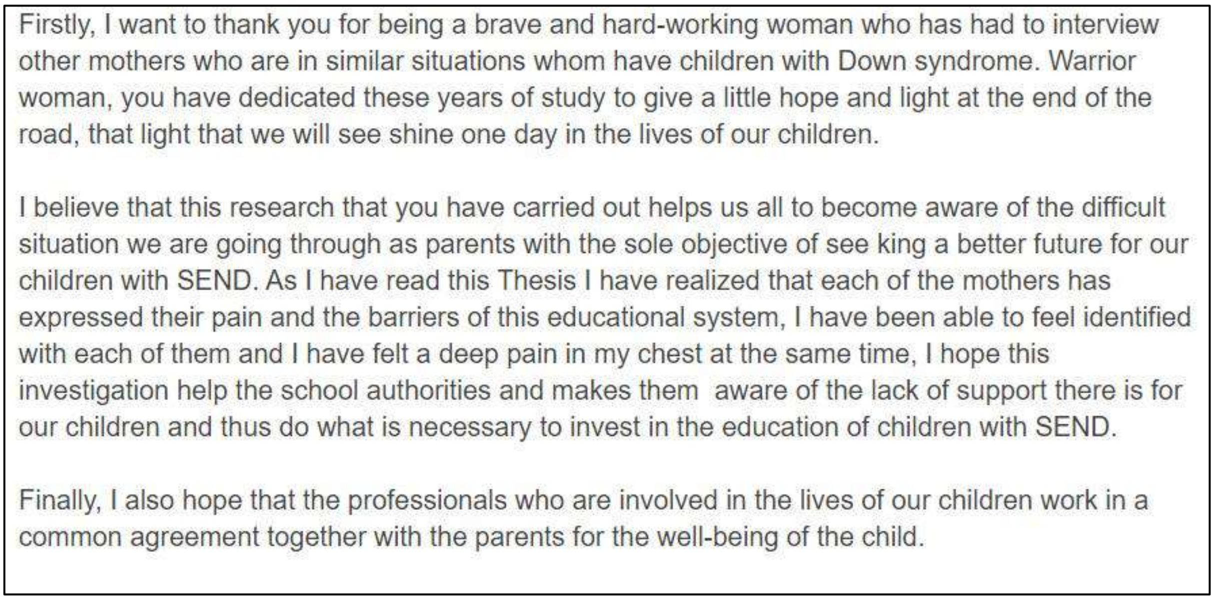
Anne described how '*it has been therapy, thank you'* and Emily described how '*it has been a really good mental wellbeing space to brain dump the here and now but also reflect on the past, so actually, I've found that quite good therapy if that makes sense'*. Although she recognised '*it is a commitment'* she described how I had made it '*easy'* and how she was '*quite grateful and glad of opportunities like this, where I've got to sit and just do nothing almost*'. Clare similarly described the research inquiry:

> *I've really enjoyed it, and I found it therapeutic. honesty, because, you know, when when you hit these bumps in the road as a Special, I feel quite emotional, as a Special Needs parent erm you know*' and went on to say '*You know, you feel so overwhelmed. You know, like, when the tribunal gets called, or you know, something happens, you feel so overwhelmed. And you can't just reach out and talk to your friends about it, because they don't understand it's so convoluted to start from, you know, square one and explain the whole thing, it would just take days. So quite often, you just sort of go*

> *[breathes in] I am really stressed but can't talk about it, and to actually be able to sit and talk to you and to have, you know, having a few hours of your time and you know how it works. And you know, you can empathise and you understand, it's been really useful for me.*

I had not really anticipated these benefits to the mothers and am obviously delighted that it offered such support especially during challenging times.

I also sent a draft copy of the thesis to all the mothers, asking for their feedback and thoughts on the content. Only Faith responded with any comments, as follows:



Firstly, I want to thank you for being a brave and hard-working woman who has had to interview other mothers who are in similar situations whom have children with Down syndrome. Warrior woman, you have dedicated these years of study to give a little hope and light at the end of the road, that light that we will see shine one day in the lives of our children.

I believe that this research that you have carried out helps us all to become aware of the difficult situation we are going through as parents with the sole objective of see king a better future for our children with SEND. As I have read this Thesis I have realized that each of the mothers has expressed their pain and the barriers of this educational system, I have been able to feel identified with each of them and I have felt a deep pain in my chest at the same time, I hope this investigation help the school authorities and makes them aware of the lack of support there is for our children and thus do what is necessary to invest in the education of children with SEND.

Finally, I also hope that the professionals who are involved in the lives of our children work in a common agreement together with the parents for the well-being of the child.

Image 22: Faith’s response to the draft thesis.

In summer 2023, I was invited to develop and produce an inclusive education campaign for the Down’s Syndrome Association[93]. Instead of seeing inclusion as dependent on specialist interventions, the campaign drew on both previous DSA research and the key messages from our conversations in this inquiry, particularly those that were presented to the DfE as

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[93] This information campaign ran between September and December 2023. See https://www.downs-syndrome.org.uk/our-work/services-projects/education-project/ for details.

previously discussed. I produced a range of new resources for educators, eg. to support friendships, inclusive residential trips or sports days, and how to educate about disability throughout the curriculum.

12.8 Final reflections - becoming researcher

I returned to study in 2014, when my daughter was just 9. She is now 19 and has changed considerably during this time, growing in abilities, independence, and confidence. I too have changed, not just a few more wrinkles, but similarly growing in abilities, independence, and confidence both within the academic community and activist spaces. Accordingly, I would like to take the opportunity to reflect on how this journey of becoming-researcher has changed the way I have come to see myself and the world around me.

My experiences as a mother played a significant role in my writing and thinking, and I could not have undertaken this research without this being centred in my work. I have explicitly brought mothering of a disabled child/young person into academia, carving out time to ruminate and experiment with how to do this in a meaningful and respectful way, engaging in uncertainty and not knowing. I recognise the luxurious position that I have been in during the past ten years that many mothers might not have: reading widely, playing with ideas and an in-depth exploration of theory, whilst being my daughter’s primary carer and undertaking both voluntary and paid work supporting other families of disabled children. At times this has been difficult to achieve, especially during COVID-19 and the SEND tribunal, both of which I found personally challenging; however, I still recognise the fact that I am amongst the small minority who can pursue their interests in this way.

In their discussion of belonging and becoming in academia, Nygaard & Savva (2021:21) describe how ‘scholarly development “takes place in multiple processes, which are diverse in nature, and usually happen in traditional and non-traditional sites of learning”’, which can include engagement with other students, additional courses, and reading outside of the traditional boundaries. To develop my skills and knowledge of what it means to ‘be’ a researcher, I have taken advantage of as many opportunities as possible, including attending a range of training courses, presenting at and organising events and conferences, attending webinars or taking part in optional activities, eg. workshops to learn about the use of images when communicating research or how to write exhibition text. I have also joined in dissemination activities such as writing for the Postgraduate Research (PGR) development blog[94], submitting a collage to the PGR Images of Research competition[95], and submitting an entry for the PGR Almanac exhibition[96]. These have often been playful encounters, affording opportunities to explore new approaches to communication and engagement. I believe these activities have helped me to develop valuable skills and innovative approaches to undertaking and disseminating research.

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[94] https://uobpgrdevelopment.wordpress.com/2023/03/06/being-a-woman-and-a-pgr-at-uob/

[95] https://www.canva.com/design/DAFk9jrHVR0/Iz4WbwzS4lPr6du8aWeWyA/edit?utm_content=DAFk9jrHVR0&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

[96] See 15 February https://www.sutori.com/en/story/the-postgraduate-research-almanac--6VsZ6PCMohE17qVBrNN2S4EJ

As Mahon & Henry describe, the etymological roots of ‘to research’ are ‘in the Middle French *recercher* (meaning “to seek out, or to search closely”) which goes back to the Latin *circare* (meaning “go about, wander, traverse”)’ (Mahon & Henry, 2022:25, original emphasis). The process of becoming-researcher should not be seen as ‘a clear path between two points’, instead there is an ongoing process of ‘unfolding, shifting and changing’ (Rubin, 2023:3). Importantly, I have been able to meander, to go down various rabbit holes, to follow things that glitter and shimmer, catching my attention. I have been able to ‘hang out’ with my research inquiry and the mothers who took part in it, a ‘dwelling with’ and engagement with the landscape and an openness to affective encounters, ‘carving space’ out where I have been able to both ‘wander and wonder’ (Pyrry, 2022:70). It has been an integral aspect of this inquiry that I have been able to read widely, to take time and to let my mind wander, something that is not always possible when racing to publish articles due to institutional pressures (Mahon & Henry, 2022). This has been afforded to me by having a supervisory team who were supportive, patient and trusting, yet who would also offer helpful challenge and guidance when needed. I feel honoured to have had the opportunity to engage in this research inquiry, and hope that I can demonstrate the generative nature of this approach through the outputs within and beyond this written thesis.

I have had the chance to learn the customs and everyday written and unwritten rules of what it means to engage in academia, and importantly how to find ways to resist and push back against some of these in my research practice. I have come to recognise that undertaking research – including research for a PhD that is often considered a solo endeavour – is never something you do alone, even when I was sat in my bedroom alone throughout the inquiry and writing this thesis. As Bowstead (2021:123) describes, 'research is not something we stand outside of "looking in"' rather, it is 'an entangled embodiment of multiple becomings'. I recognise how I am 'be(com)ing in relation to other-than-humans in the world, of which both humans and other-than humans are actively part of producing' (Østern et al., 2023:284). I am not 'an autonomous researcher who can think the world from a distance, a knowing subject separate from its spatial relations' (Pyrry, 2022:66). As Ribenfors (2021:unpaginated) describes it is important to approach the PhD as a 'research assemblage' which:

> brings forth the complexity and the interconnectedness of research, the entangling of ourselves, our personal lives, research participants, supervisors, buildings, ideas, books, technologies, fears, desires and so on. Each element within this assemblage having the capacity to affect and be affected, to alter the course of events.

As becoming-researcher, I understand myself as 'becoming-with the multiplicity' (Manning, 2016:75) within a 'constellation of humans, objects, practices and ideas present in relation with one another' (Rubin, 2023:51), as I have attempted to depict below[97].

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[97] Recognising, of course, that it is impossible to include everything and that the assemblage within which I am becoming is ever shifting.

Image 23: Research assemblage

An important part of my academic praxis is to find others who I can dance with and to see where this may lead (Pirrie et al., 2022). I appreciate the wonderful women that I have met and now consider to be dear friends during this journey, those who equally seek to think differently about what it means to engage in research and scholarship. Together we take up space and create places of possibility where we 'reinstate the centrality of ethical relations among us' (Pirrie et al., 202:20-21), as we read, write, and create together. During the last four years, I have been presented with various opportunities to write articles and chapters, both individually and in collaboration, that were interesting and generative in my thinking, as side-projects to this doctoral thesis. I have been able to work out who I want to be as 'a researcher' through collaborating and learning with and from others.

Finally, I have come to recognise that ‘materials, discourses, practices and affects’ matter and that I am becoming ‘in relation with everything and everyone else’ (Rubin, 2023:62). I hope to hold on to this when I feel the inevitable ‘mum guilt’ about whether I have done enough for my daughter, or when relationships with professionals break down. My experiences within academia and my engagement with theory therefore helps me recognise the way that I am not an isolated individual but that we are all entangled and how there are various relations and events that shape our identities, and the possibilities open to us. Additionally, the theories I have become familiar with help me recognise the benefits of affirmative action and micro-affordances, and that I do not have to always engage in critique or negativity even when dealing with stressful encounters with the LA. I can find possibility even in moments of darkness, refusing to lose sight of what matters or the relations that I am entangled in.

It is important to me that this research attempts to alter the material circumstances of disabled people and their families, and that it hopefully contributes to greater inclusion, rather than it being an isolated theoretical discussion that does not produce any change in the world (Allan, 2010). As I continue to struggle with ideas and thinking about inclusion, I hope that this inquiry will arouse and persuade those reading it to think differently about inclusion and exclusion, as they potentially ‘see something other than their own view of the world’ (Allan, 2010:613)[98] or to engage creatively when undertaking research with mothers of disabled children. I do not know what disturbances this thesis might make, how it might ‘unsettle, push boundaries and norms, and disrupt hierarchies and the status quo’ (Guyotte,

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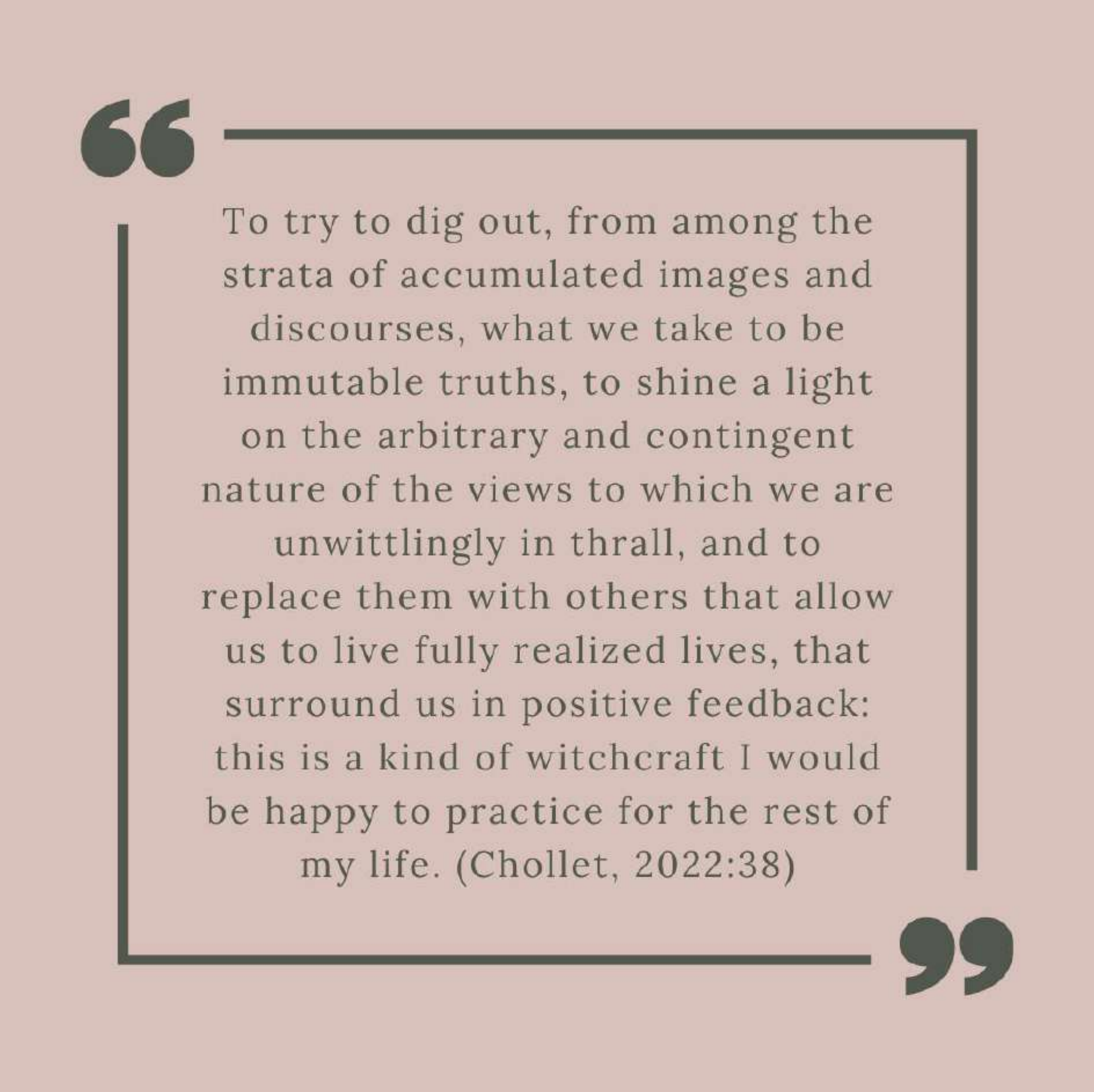
[98] I presented the creative research aspects of this inquiry at an Open Space event run by CANI-NET and one of the attendees thanked me for including her in my world, a world she had not had any real knowledge or experience of prior to my presentation.

2023:101), but I hope that it has an impact and can make a positive difference for disabled children and their families. This thesis attempts to complicate rather than explicate (Allan, 2011), to affect, to produce ripples that might turn into waves of change. I therefore invite each reader of this thesis to put to work the ideas presented within this thesis in a way that makes sense to them, to take them forward in their becoming.



To try to dig out, from among the strata of accumulated images and discourses, what we take to be immutable truths, to shine a light on the arbitrary and contingent nature of the views to which we are unwittlingly in thrall, and to replace them with others that allow us to live fully realized lives, that surround us in positive feedback: this is a kind of witchcraft I would be happy to practice for the rest of my life. (Chollet, 2022:38)

Image 22: Witchcraft

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BEING 'MUM': APPROACHING THE SUBJECTIVITY OF MOTHERS OF DISABLED CHILDREN AS BECOMING TO EXPLORE EDUCATION INCLUSION AND EXCLUSION

by

SHARON LOUISE SMITH

A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF PHILOSOPHY

PART TWO OF TWO - APPENDICES

Department of Inclusion and Special Needs

School of Education

College of Social Sciences

University of Birmingham

March 2024

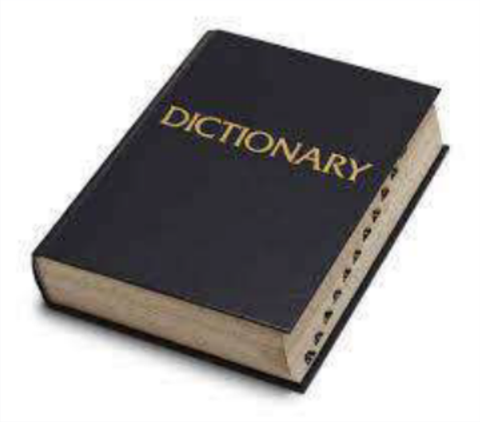
APPENDIX ONE - EASY READ VERSION

1. Introduction

My name is Sharon Smith.

I have a daughter who has Down syndrome.

I have written this Easy Read booklet to tell you about some **research** I have been doing.



To do **research** means to find out new information about something that you are interested in.

2. What was the research about?

I wanted to find out about the choices that mothers have about which school their disabled child should go to.

In 2021 and 2022 I talked to seven different mothers who have a child who has Down syndrome.

Their children all go to school.

We met together in houses and cafes. We also talked on the telephone and sent messages using email.

We spoke to each other lots of times during the year.

3. What we talked about

We talked about what it was like for their child to go to school.

We talked about the times when things went well for their child in school.

We also talked about the times when things did not go well for their child in school.

We talked about their dreams for their child in the future.

We also talked about their worries for their child's future.

We talked about how they must fill in lots of forms to get help for their child.

This means that they have lots of paperwork in their houses.

We talked about the many meetings that mothers must go to, to talk about their child's education.

We talked about the role mothers have in these meetings.

Sometimes professionals do not send reports on time.

Sometimes professionals do not come to meetings.

Sometimes mothers can feel angry and not listened to.

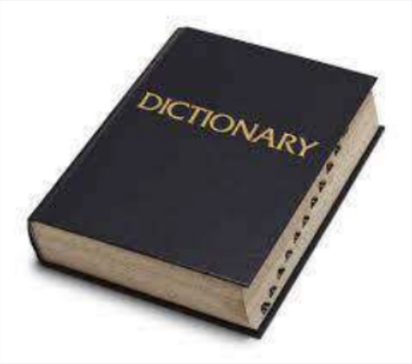
They think they must shout louder to be heard.

We also talked about how lots of people want to give advice to mothers about the best type of school.

This advice and information can be confusing.

It can be stressful for mothers when they are choosing the best school for their disabled child.

They might not know whether to choose a mainstream school or special school.



A **mainstream school** is the school that most children from a local area go to.

Special schools are only for children who are disabled or have been labelled as having special educational needs.

Sometimes schools will tell mothers that their child cannot go there.

Mothers sometimes must visit lots of schools before they find one that is happy to welcome their child.

4. What I found out

a) Documents

The piles of documents and paperwork sent home by school can be upsetting for mothers.

b) Mother's roles in education

Mothers work hard to make schools better for their disabled child.

- They go on training courses.
- They learn the law.
- They help their child to learn.

Sometimes this work is hidden. This means that we must look carefully to find out what work they are doing, to help schools learn what needs to change.

Mothers of disabled children can have good ideas about what needs to change in education.

This is because they know the different things that are not working for their child, and they know the things that will help them.

c) How mothers make decisions about schools

Mothers are sometimes told stories that make them think their disabled child will be bullied or not have friends in the future.

Mothers get sad when they see their children being left out.

And when they do not get invited to birthday parties and playdates.

Mothers sometimes have memories of going to school and not knowing any disabled children.

These memories can join together with their worries about the future.

This can make mothers even more worried about sending their child to mainstream school.

This might mean that they choose a special school instead.

5. What needs to change

Schools should not turn disabled children away because the child is disabled.

Schools and professionals should listen to mothers of disabled children and to disabled children about how schools can change.

They need to listen to their worries and the challenges they face.

People working in education, disabled children and their parents should meet to share their ideas for change.

Professionals must make the time and space for this work to be done, so that more disabled children can be included in mainstream education.

It is important to think about different ways for disabled children and their parents to have a say in what a good education for all children looks like.

APPENDIX TWO – ETHICS APPLICATION

UNIVERSITY OF
BIRMINGHAM

Application for Ethics Review Form

Guidance Notes:

What is the purpose of this form?

This form should be completed to seek ethics review for research projects to be undertaken by University of Birmingham staff, PGR students or visiting/emeritus researchers who will be carrying out research which will be attributed to the University.

Who should complete it?

For a staff project – the lead researcher/Principal Investigator on the project.
For a PGR student project – the student's academic supervisor, in discussion with the student.

Students undertaking undergraduate projects and taught postgraduate (PGT) students should refer to their Department/School for advice

When should it be completed?

After you have completed the University's online ethics self-assessment form (SAF), IF the SAF indicates that ethics review is required. You should apply in good time to ensure that you receive a favourable ethics opinion prior to the commencement of the project and it is recommended that you allow at least 60 working days for the ethics process to be completed.

How should it be submitted?

An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk.

What should be included with it?

Copies of any relevant supporting information and participant documentation, research tools (e.g. interview topic guides, questionnaires, etc) and where appropriate a health & safety risk assessment for the project (see section 10 of this form for further information about risk assessments).

What should applicants read before submitting this form?

Before submitting, you should ensure that you have read and understood the following information and guidance and that you have taken it into account when completing your application:

The information and guidance provided on the University's ethics webpages (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx)

The University's Code of Practice for Research (https://www.birmingham.ac.uk/Documents/university/legal/research.pdf)

The guidance on Data Protection for researchers provided by the University's Legal Services team at https://intranet.birmingham.ac.uk/legal-services/What-we-do/Data-Protection/resources.aspx.

Section 1: Basic Project Details

Project Title: Being 'mum' – the subjectivity of parents of children with Special Educational Needs and Disability and its impact on inclusion

Is this project a:

University of Birmingham Staff Research project ☐

University of Birmingham Postgraduate Research (PGR) Student project ☒

Other (Please specify below) ☐

Details of the Principal Investigator or Lead Supervisor (for PGR student projects):

Title: Professor

First name: Julie

Last name: Allan

Position held: Head of School of Education

School/Department School of Education

Telephone: +44 121 414 4853

Email address: [redacted]

Details of any Co-Investigators or Co-Supervisors (for PGR student projects):

Title: Dr

First name: Clara

Last name: Joergensen

Position held: Research fellow

School/Department School of Education

Telephone: +44 121 415 8170

Email address: [redacted]

Details of the student for PGR student projects:

Title: Mrs

First name: Sharon

Last name: Smith

Course of study: PhD Education

Email address [redacted]

Project start and end dates:

Estimated start date of project: TBC
Estimated end date of project: TBC

Funding:

Sources of funding: Self-funded plus winner of 2019 BERA doctoral fellowship - £5k pa stipend for 3 years

Section 2: Summary of Project

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon - please explain any technical terms or discipline-specific phrases. Please do not provide extensive academic background material or references.

This research study intends to explore how discourses, through policy and practice, as well as wider societal pressures, determine how parent carers of children with SEND understand their identities and experiences, and how this subsequently impacts on their interactions with the education system. It will explore how discourses construct the identity of 'mum', a frequently used short-hand that describes the role parents take within education interactions and practice, and how/why some parent carers resist this construction and attempt instead to subvert or disrupt the education system in order to seek a suitable education for their child.

Furthermore, it will seek to explore how individual experiences and understandings impact parents' views about what effective inclusion in education looks like, whether inclusion is something they desire or do not hold as important, and how this impacts the choices they make in relation to their child's education.

Research questions:

- How is the role of parents of children with SEND articulated within official documents and policy?

- How do parents of children with SEND understand their role, experiences and identities?
- What discourses inform the way parents construct their experiences and identities?
- What role do parents play in co-producing discourses that have power effects on themselves and other parents?
- How do parents resist discourses at a collective or individual level, seeking alternative ways of being?
- What is the impact of discourses related to parent carers in relation to inclusion in education?

This research study intends to explore both how discourses and power create parents as subject, but also looking at how they too are enacting this through how they constitute themselves. The research has been designed to elicit participants' personal views of their subjective experience as they understand it, in order to explore their motives and reasons for acting, how the situation looked to them at specific stages of their child's education and what options and alternatives they saw open to them. Research participants will be invited to provide copies of any existing written material that helps them describe or think about their experiences, for instance extracts from social media, personal diaries, blogs and their 'Our Story' submissions for EHCP assessments, written at specific points in their child's education. This will provide rich material for discussion, as it will be their articulation of their understandings and experiences that was written either as part of the educational process, or as their own personal reflection and/or sharing of their experiences.

While the intention is to record and transcribe the spoken words within interactions with participants, participants will also be encouraged to generate embodied accounts using methods such as photos, diaries, copies of documents produced as part of their interactions with the education system and historical social media or blog/website content. It is important to recognise that the use of social media and blogs may be used by particular groups of parents as a way of constructing meaning and subjectivity, and it is important that the study includes parents who may not document their experiences in writing. Given that this is an inclusive piece of research, it is necessary to remove the privilege given to the written word and to allow participants to represent their experiences in a manner which they feel reflects most closely to their thoughts and feelings. Therefore, alternative approaches will be encouraged, such as photo elicitation, giving participants options about how they want to present their experiences. The material participants provide will form the basis for engagement based on a conversational approach, that seeks to explore how parents construct meaning around lived experiences.

It is necessary to consider how the research process itself might be a form of subjectification, as the subject may be further constituted during interactions with the researcher, or the engagement might provide an opportunity to recognise alternative ways of seeing their experiences, both of which may impact on their future enactment of self. As participants will be asked to select the written or photographic material they want to use as the basis of the interview, they are able to have greater control of the agenda and direction of the discussion.

The researcher is approaching this research as a parent carer and will therefore interact with participants with understanding and empathy. They bring their own experiences and understandings to the research study, therefore there it will need to be acknowledged that they will constitute meanings and interpretations that cannot be separated from their own understanding of self.

Section 3: Conduct and location of Project

Conduct of project

Please give a description of the research methodology that will be used. If more than one methodology or phase will be involved, please separate these out clearly and refer to them consistently throughout the rest of this form.

This study will be undertaken as an ongoing ‘conversation’ between the researcher and individual participants. Each participant will be an individual ‘case study’ and the research design is one of a series of semi-structured informal interviews, with built in periods of reflection for both the researcher and the participant.

There will be a number of stages to the research design:

Stage one – Preparation

Participants have an initial period of reflection about their experiences (a prompt sheet will be provided to assist with this), and they will be asked to bring one or more written or visual artefacts to help guide the initial conversation (existing reports or diaries, or photographs/items that are useful as a prompt, or they might choose to write or draw their own story for discussion).

Stage two – Conversation

A series of semi-structured interviews will take place either face to face or using telephone/online video technology. In advance of each of these, the participants will be asked to reflect on discussions to date about their role as a parent, and to think about what they would like to discuss in the next stage of the conversation, drawing on the prompts they have chosen to bring to aid discussion. After each engagement, the researcher will type up notes and a transcript of the recorded conversation and will send it to the participant to use to reflect on before the next interview. The number of interviews will be determined in agreement with the participants, depending on how the conversation is developing and whether there is still more that needs to be discussed.

Stage three – Final Reflection

Here the researcher and participant will each reflect on the whole conversation they have had and what they might have learnt or how they might have changed their perspective on a particular topic. The researcher and participant will come together for one final reflection session to do this. The participants will also have the opportunity to feedback and agree how they and their family are represented in the report for the thesis.

Geographic location of project

State the geographic locations where the project and all associated fieldwork will be carried out. If the project will involve travel to areas which may be considered unsafe, either in the UK or overseas, please ensure that the risks of this (or any other non-trivial health and safety risks associated with the research) are addressed by a documented health and safety risk assessment, as described in section 10 of this form.

England

Section 4: Research Participants and Recruitment

Does the project involve human participants?

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

Yes ☒

No ☐

If you have answered NO please go on to Section 8 of this form. If you have answered YES please complete the rest of this section and then continue on to section 5.

Who will the participants be?

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

Adults over 18 years old, living in England, who are parents of children who have Down syndrome. It will be limited to parents of children who are 4-18 years old, the age range that relates to the age of required participation in education or training in England. The study is open to both mothers and fathers, and parents who have adopted or are fostering a child with Down syndrome.

The study will exclude any parents with whom the researchers has any existing relationship with, ie any members of the Down syndrome support group they co-founded, any of their own personal friends or contacts, and their 'friends' on social media who also have a child with Down syndrome.

It is anticipated that there will be between 5-10 participants, as this is intended to be a small scale study that has a focus on creating rich, vibrant and detailed material with participants, over a sustained period of time. If I recruit more than ten potential participants, I will use filter techniques in an attempt to ensure that both mothers and fathers are involved, a range of ages of children are included, that there is a mixture of mainstream/special school placements and if possible that minority groups are represented. However, this study is not intended to be representative and therefore ensuring diversity of participants is desired rather than a key requirement.

How will the participants be recruited?

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student). Please ensure that you attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

Parents will be recruited through the following routes:

Direct contact to UK based Down syndrome organisations, parent support groups or pan-disability Parent Carer Forums, to ask them to share the advert with their members

Direct contact to schools to ask them to share the advert with parents who have a child with Down syndrome

Section 5: Consent

What process will be used to obtain consent?

Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are under the age of 16 it would usually be necessary to obtain parental consent and the process for this should be described in full, including whether parental consent will be opt-in or opt-out.

Explicit, freely-given and fully informed consent will be sought from participants. Participants will be provided with an information overview document, which will explain the rationale and structure of the project, as well as the potential benefits and risks of their involvement. They will also be provided with a consent form to sign before the research relationship will commence. However, before signing, an initial informal telephone/video call will be scheduled with interested participants, to discuss the study in greater detail and to answer any initial questions they may have. Participants can also correspond further via email or telephone/video contact if they wish, before agreeing to take part. These discussions will not form part of the research and will not be recorded. The researcher will not rush participants, or put any pressure on them to take part.

Participants will be asked to sign and return a written consent form if they are happy to be involved in the research. The researcher will also sign the form to provide a written commitment to participants taking part in the research. A copy of the form that has been signed by participants and researcher will be returned to participants for their keeping.

The key aims of this initial contact will be to ensure that:

- Participants understand the nature and focus of the research
- Participants understand that they can withdraw at any time without giving reasons and they will not be penalised for withdrawing
- Participants understand how the research process is not fixed at the outset, but will evolve during the engagement, and therefore it is not possible to predict how many interactions will take place, what time period or commitment the research will require, or what information or artefacts (photographs, blogs/social media, documents, diaries etc) the participant might want to share
- Participants understand that they do not have to share any information or artefacts that they do not feel happy about disclosing or sharing
- Participants understand that they can provide or withdraw consent for recording of interactions at any point in the process
- Participants understand that they can ask for specific aspects of the research to be excluded from the reporting of the research or to be deleted from the data storage at any time, should they change their mind about sharing it (however they will need to recognise that the researcher may have been influenced in their thinking by things that they have already seen or heard)
- Procedures relating to confidentiality and safeguarding have been clearly explained

- Participants have the opportunity to raise concerns or ask questions before they agree to take part in the study

This written consent that is obtained at the outset of the research is only the first occasion that consent will be sought in the ongoing research process. Prior to each planned meeting or telephone call, the researcher will obtain verbal consent for the participant's ongoing involvement with the study, to ensure that they are happy with the way that the research is developing, including the analysis that has been taking place during the research (ie how they are being represented by the researcher), and to secure their ongoing commitment. This will be an opportunity to discuss any concerns or ask any further questions about their participation.

Participants will have the opportunity to withdraw from the research at any point, and can choose whether the information and artefacts they have provided can still be used by the researcher or whether they should be deleted and not used within the study. If they wish to withdraw consent there will be no repercussions. They can withdraw up to three calendar months after the final reflection interaction.

Please be aware that if the project involves over 16s who lack capacity to consent, separate approval will be required from the Health Research Authority (HRA) in line with the Mental Capacity Act. N/A

Please attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

Note: Guidance from Legal Services on wording relating to the Data Protection Act 2018 can be accessed at https://intranet.birmingham.ac.uk/legal-services/What-we-do/Data-Protection/resources.aspx.

Use of deception?

Will the participants be deceived in any way about the purpose of the study?

Yes ☐

No ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and the nature of any explanation/debrief will be provided to the participants after the study has taken place.

N/A

Section 6: Participant compentsation, withdrawal and feedback to participants

What, if any, feedback will be provided to participants?

Explain any feedback/ information that will be provided to the participants after participation in the research (e.g. a more complete description of the purpose of the research, or access to the results of the research).

The research design is such that there will be iterative feedback throughout the research engagement, during informal conversations and interviews in order to reflect together as an ongoing inductive process. Participants will be asked to reflect on transcripts of previous conversations, and also on their own and the researcher's observations or ongoing reflections. Participants will be provided with a copy of the final analysis/conclusions, and will be able to provide their thoughts, which will be incorporated into the final thesis report. They will be provided with access to the final thesis if they wish to have a copy.

What arrangements will be in place for participant withdrawal?

Describe how the participants will be informed of their right to withdraw from the project, explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

Participants will be notified in the initial communication/consent form that they have a right to withdraw from the project at any point. Should they choose to withdraw, then their data will be deleted and not used for the research study. However, it is necessary to note that the interactions to this point will have potentially influenced the researcher's understanding and could therefore although they are withdrawing their presence in the research will have had an impact on the final thesis report.

Please confirm the specific date/timescale to be used as the deadline for participant withdrawal and ensure that this is consistently stated across all participant documentation. This is considered preferable to allowing participants to 'withdraw at any time' as presumably there will be a point beyond which it will not be possible to remove their data from the study (e.g. because analysis has started, the findings have been published, etc).

Participants can withdraw from the study at any point up to three calendar months after the final reflection interaction. They will be asked when they decide to withdraw whether they wish for information related to their involvement to be included within the study or whether all material/records should be immediately deleted.

If they state that they do not want any of their involvement including in the thesis then all records will be deleted at this point. However, if they agree to have their involvement included within the research but then subsequently decide they wish to withdraw consent, their information will not be included in any future unpublished written or oral reports, as far as it is possible to disambiguate.

What arrangements will be in place for participant compensation?

Will participants receive compensation for participation?

Yes ☐

No ☒

If yes, please provide further information about the nature and value of any compensation and clarify whether it will be financial or non-financial.

N/A

If participants choose to withdraw, how will you deal with compensation?

N/A

Section 7: Confidentiality/anonymity

Will the identity of the participants be known to the researcher?

Will participants be truly anonymous (i.e. their identity will not be known to the researcher)?

Yes ☐

No ☒

In what format will data be stored?

Will participants' data be stored in identifiable format, or will it be anonymised or pseudo-anonymised (i.e. an assigned ID code or number will be used instead of the participant's name and a key will kept allowing the researcher to identify a participant's data)?

This research relates to human subjects (parents of disabled children) and is therefore sensitive personal data.

All participants will provide written signed consent prior to commencement of the research, in which they consent to their data being stored and shared in research dissemination (conferences, papers, book chapters for example). They can withdraw from the study at any time and can ask for their data to be deleted.

All participant data will be anonymised and will be allocated a pseudonym as soon as they agree to take part in the research. The researcher will keep a password protected excel file with actual names and pseudonyms. Participants can choose their own pseudonym if they wish. Participants' identities will be kept confidential, only the researcher will know the identity of participants.

Each research participant will have their own folder, in which all information relating to them will be stored electronically online. This will be named using their pseudonym rather than their real name. All files will use the following structure <pseudonym/date/information type> (for instance Sharon210320email.pdf)

If participants choose to provide copies of any documentation that includes any identifying information, these will be scanned/saved electronically and all identifying information will be redacted on saved versions. Original copies will be returned to the participant or if they are photocopies that do not need returning, they will be shredded using a secure data collection service.

The researcher will only use University of Birmingham email for corresponding with participants. This is stored in the cloud and is password protected. She will delete all emails once they have saved a PDF version in the participants' data file as detailed previously.

Due to the proposed methodology, data will come from a number of potential sources, depending on how the conversation develops and what information or resources the research participants might want to discuss or use as a prompt. The research therefore might generate (but is not limited to) the following:

- audio or video recordings eg from interviews or discussions with participants either face to face or online. This could consist of recordings taken on the researcher's telephone or an audio recording device (both of which will be used to record discussions with participants to ensure a backup copy should one device fail) or Zoom recordings of webchat discussions

- typed transcripts from interviews/engagement with participants
- researcher's records of observations, summaries after engagement, reflections eg emotions/feelings or how the data links to theory or specific topics related to the research, notes summarising telephone conversations etc.
- participants might provide copies of photos, letters, reports, social media posts/blogs, entries from personal diaries or other visual/written material
- participants will be invited to provide comments or feedback on the researcher's observations or analysis, which could be in verbal or written form

The data will be generated over a sustained period of engagement with no more than ten research participants. Each participant's file is likely to generate different types of data, depending on how the research progresses.

Will participants' data be treated as confidential?

Will participants' data be treated as confidential (i.e. they will not be identified in any outputs from the study and their identity will not be disclosed to any third party)?

Yes ☒

No ☐

If you have answered no to the question above, meaning that participants' data will not be treated as confidential (i.e. their data and/or identities may be revealed in the research outputs or otherwise to third parties), please provide further information and justification for this:

Section 8: Storage, access and disposal of data

How and where will the data (both paper and electronic) be stored, what arrangements will be in place to keep it secure and who will have access to it?

Please note that for long-term storage, data should usually be held on a secure University of Birmingham IT system, for example BEAR (see https://intranet.birmingham.ac.uk/it/teams/infrastructure/research/bear/index.aspx).

The researcher will store the following documents as follows:

scanned copies of any handwritten notes from their own thoughts/observations/reflections relating to engagement with participants

any photographs/written material provided by participants

all typed notes/observations/reflections relating to engagement with participants

typed up copies of transcripts of recorded interviews or discussions with participants

copies of email correspondence sent to or by participants

all original audio and video files

will be uploaded electronically to the University of Birmingham OneDrive (a cloud based system) which is encrypted and then secured by two-step verification and an auto lock after three minutes of inactivity.

Back-up copies of all files will be stored as follows:

On University of Birmingham BEAR storage (the university's Data Store)

The researcher will update and back up files daily during the period in which they are undertaking empirical research and throughout any subsequent analysis.

If any photos or videos provided by participants show people on them, the researcher will write a description of the photo/video, which will be checked with the participant for accuracy, and will then delete the original in order to protect their identity.

The researcher is the only person who will be able to access the data, however it will need to be shared with her supervisors for supervision purposes.

The data will be used for writing the researcher's PhD thesis. Additionally it will be shared in research dissemination activities such as presentations or written papers/chapters. Pseudonyms will be used in all instances. Participants will be required to provide written consent for this at the outset of the research. If they do not wish their data to be shared further at any point they can withdraw this consent and their data will not be used in any further oral or written presentations.

The researcher will only share anonymised data in other instances if they have obtained explicit participant permission for the particular situation. Otherwise, the data will not be shared with a wider audience. This research is not funded by a research body and therefore there is no expectation or requirement that the data will be made more widely available after a specific period of time.

Data retention and disposal

The University usually requires data to be held for a minimum of 10 years to allow for verification. Will you retain your data for at least 10 years?

Yes ☒

No ☐

If data will be held for less than 10 years, please provide further justification:

N/A

What arrangements will be in place for the secure disposal of data?

Anonymised data will be stored on University of Birmingham's Research Data Archive for 10 years. Once transferred the data will be set to read-only to prevent any inadvertent additions or deletions of the dataset. Any changes will result in a new dataset, which will be archived separately.

Data will be stored for 10 years, should access to the data be requested within a 10 year period, the 10 year clock is then reset from the point of last access. After the 10 year period the data will be deleted.

Section 9: Other approvals required

Are you aware of any other national or local approvals required to carry out this research?
No

E.g. clearance from the Disclosure and Barring Service (DBS), Local Authority approval for work involving Social Care, local ethics/governance approvals if the work will be carried out *overseas, or approval from NOMS or HMPPS for work involving police or prisons? If so, please provide further details:*

A DBS check will not be required as the researcher will not be alone with any children. However, the researcher does have existing current DBS clearance due to her role as a trustee for two SEND charities, and if the ethics board would like her to obtain one for this research, is willing to obtain another.

For projects involving NHS staff, is approval from the Health Research Authority (HRA) needed in addition to University ethics approval? *N/A*

If your project will involve NHS staff, please go to the HRA decision tool at http://www.hra-decisiontools.org.uk/research/ to establish whether the NHS would consider your project to be research, thus requiring HRA approval in addition to University ethics approval. Is HRA approval required?

Yes ☐ N/A

No ☐

Please include a print out of the HRA decision tool outcome with your application.

Section 10: Risks and benefits/significance

Benefits/significance of the research

Outline the potential significance and/or benefits of the research

Through an initial literature search, it is possible to identify a number of constraints and challenges parents face that act as barriers to their child's inclusion. However, how the parent themselves might be a barrier or enabler of inclusion is rarely discussed. There does not appear to be a body of literature that specifically explores the link between how parents of children with SEND understand their subjectivity and how this impacts both on their interpretations of their experiences and their approach to inclusion. This research intends to fill this gap in the literature.

Parents of disabled children often report that they feel unheard or lacking in voice. This study will allow participants the opportunity to 'tell their story' and will provide the time and space to reflect on their previous experiences, in particular to understand how their actions might have been influenced by power relations. Through this process, parents will hopefully be able to recognise power relations that lead to the exclusion of their child and will identify opportunities for thinking differently, which will hopefully lead to greater levels of inclusion for disabled children.

Risks of the research

Outline any potential risks (including risks to research staff, research participants, other individuals not involved in the research, the environment and/or society and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.) Please ensure that you include any risks relating to overseas travel and working in overseas locations as part of the study, particularly if the work will involve travel to/working in areas considered unsafe and/or subject to travel warnings from the Foreign and Commonwealth Office (see https://www.gov.uk/foreign-travel-advice)*. Please also be aware that the University insurer, UMAL, offers access to RiskMonitor Traveller, a service which provides 24/7/365 security advice for all travellers and you are advised to make use of this service (see https://umal.co.uk/travel/pre-travel-advice/).*

The outlining of the risks in this section does not circumvent the need to carry out and document a detailed Health and Safety risk assessment where appropriate – see below.

As the research explores personal stories, this means there is a potential for topics covered to resonate and cause upset. Whilst parents of disabled children are not necessarily vulnerable, there are additional stresses and concerns that come from being a parent of a disabled child, and therefore it is possible that they may feel vulnerable discussing certain subjects. Emotional distress is both complex and multifaceted and can occur at unexpected times and moments. Participants will be advised that they do not need to answer any questions that they feel uncomfortable with. Engagement with participants will be stopped should participants display any distress, and will not continue until the participant feels ready. If the specific engagement needs to end for the day and continue at another time, the researcher will undertake follow up contact, to ensure that the participant feels comfortable with continuing with the research and to offer signposting to support organisations if appropriate. Participants will be able to withdraw from the study at any point, if they feel it is too difficult to continue, up to three calendar months after the final reflection interaction.

Participants will be able to choose whether they want the engagement (meeting or telephone call) to be recorded or not.

Participants will be able to choose their own pseudonym. If they do not wish to do so, the researcher will allocate a pseudonym to ensure that they cannot be identified.

As well as ethical protocols, this research has been designed and will be implemented in a way that ensures ethical practice at all times. Participants will be asked to reflect on their involvement in the research, at each stage of the research, and their views and experiences will be considered fully and sensitively at all times.

The researcher will be able to provide information about support organisations, should a participant seem distressed and want further support.

Engagement with participants will be guided by participants and the developing research. Participants will have input about when and where any meetings or telephone calls will take place. It is anticipated that research will be undertaken either in neutral venues (such as a community centre/hall), in the participants' own home, or any other location that they feel is familiar and comfortable for them. It is recognised that parents of disabled children have numerous claims on their time, and life can be unpredictable and stressful. Therefore, meetings and phone calls will be arranged at times to suit participants' existing commitments and demands on their time. All participants will be contacted in advance of the meeting to check that it is still suitable to meet/speak, or whether another time would be preferable. The period of research will be determined in conjunction with the participants, rather than specified in advance. This is because it might take a longer period of time due to unexpected changes in circumstances or calls on participants' time.

The researcher will ensure that all meeting times are arranged in advance and that another person is aware of the locations and times of planned meetings.

The researcher is engaging with parents of disabled children and will not be engaging with children. However, it is possible that, at times, participants' children will be present. The researcher will ensure that they are not left alone with a child at any time.

Should an adult or child safeguarding risk be disclosed at any point during the research, then the researcher will follow this procedure:

In an emergency or if a crime has been committed:

- Call 999 and ask for the Police if someone is in immediate danger
- Contact either the local Children's Services or Adult Social Care duty team to report the safeguarding concern as soon as possible

- Advise supervisor that a safeguarding concern has arisen and been reported according to this protocol

It will be made clear to participants that legal guidelines will be followed in this instance and that confidentiality will be secondary to safeguarding in these circumstances. The researcher has undertaken safeguarding training, and is aware of the warning signs of abuse and procedures to follow.

University Health & Safety (H&S) risk assessment

For projects of more than minimal H&S risk it is essential that a H&S risk assessment is carried out and signed off in accordance with the process in place within your School/College and you must provide a copy of this with your application. The risk may be non-trivial because of travel to, or working in, a potentially unsafe location, or because of the nature of research that will carried out there. It could also involve (irrespective of location) H&S risks to research participants, or other individuals not involved directly in the research. Further information about the risk assessment process for research can be found at https://intranet.birmingham.ac.uk/hr/wellbeing/worksafe/policy/Research-Risk-Assessment-and-Mitigation-Plans-RAMPs.aspx.

Please note that travel to (or through) 'FCO Red zones' requires approval by the University's Research Travel Approval Panel, and will only be approved in exceptional circumstances where sufficient mitigation of risk can be demonstrated.

Section 11: Any other issues

Does the research raise any ethical issues not dealt with elsewhere in this form?

If yes, please provide further information:

N/A

Do you wish to provide any other information about this research not already provided, or to seek the opinion of the Ethics Committee on any particular issue?

If yes, please provide further information:

N/A

Section 12: Peer review

Has your project received scientific peer review?

Yes ☐

No ☒

If yes, please provide further details about the source of the review (e.g. independent peer review as part of the funding process or peer review from supervisors for PGR student projects):

Section 13: Nominate an expert reviewer

For certain types of project, including those of an interventional nature or those involving significant risks, it may be helpful (and you may be asked) to nominate an expert reviewer for your project. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Title:

First name:

Last name:

Email address:

Phone number:

Brief explanation of reasons for nominating and/or nominee's suitability:

Section 14: Document checklist

Please check that the following documents, where applicable, are attached to your application:

Recruitment advertisement ☒

Participant information sheet ☒

Consent form ☒

Questionnaire ☐

Interview/focus group topic guide ☐

Please proof-read study documentation and ensure that it is appropriate for the intended audience before submission.

Section 15: Applicant declaration

Please read the statements below and tick the boxes to indicate your agreement:

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent. ☒

The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it. ☒

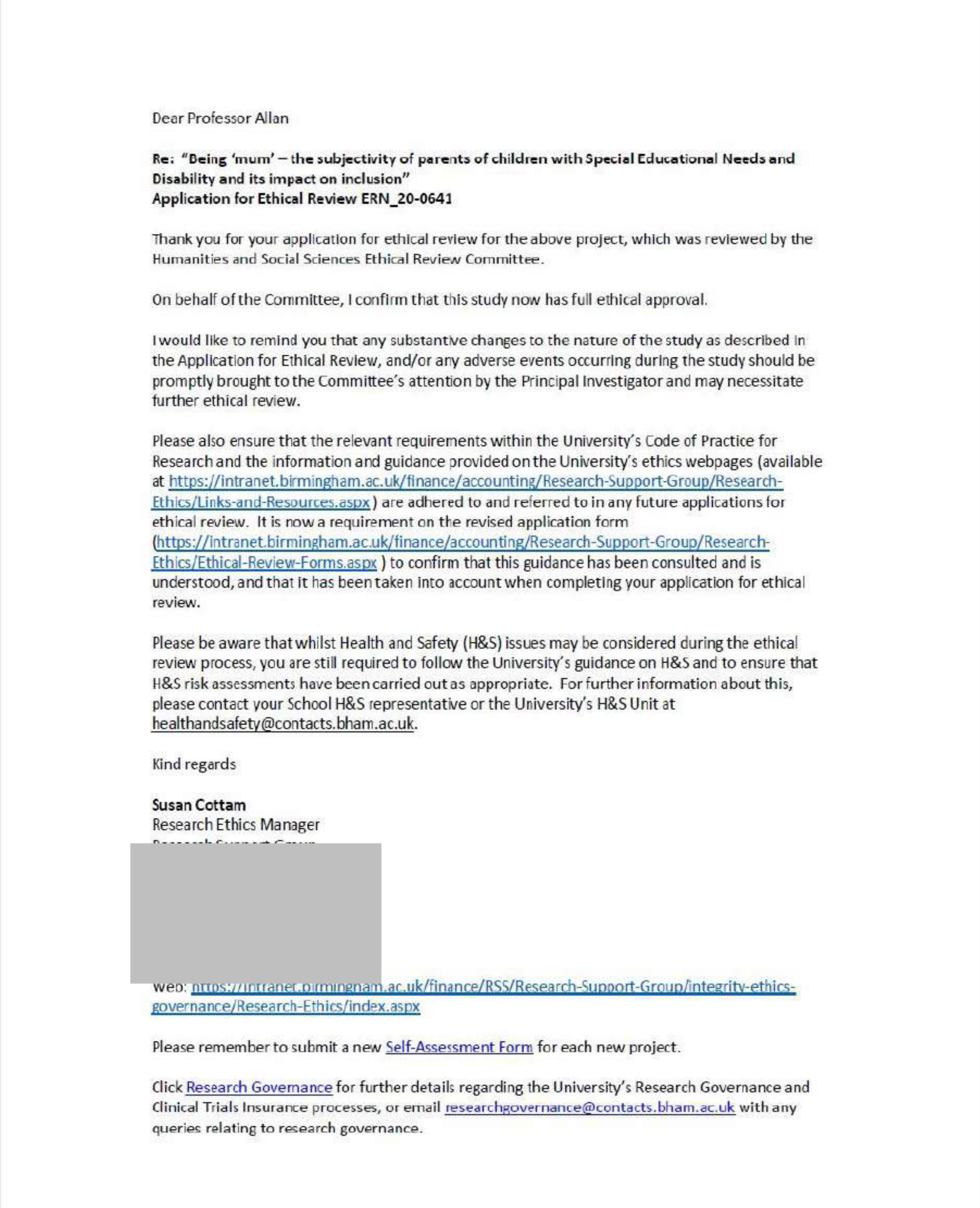
I undertake to abide by University Code of Practice for Research (https://www.birmingham.ac.uk/Documents/university/legal/research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines. ☒

I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer. ☒

I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer. ☒

Please now save your completed form and email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

APPENDIX THREE – ETHICS APPROVAL



Dear Professor Allan

Re: "Being 'mum' – the subjectivity of parents of children with Special Educational Needs and Disability and its impact on inclusion"
Application for Ethical Review ERN_20-0641

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards

Susan Cottam
Research Ethics Manager
[redacted]
Web: https://intranet.birmingham.ac.uk/finance/RSS/Research-Support-Group/integrity-ethics-governance/Research-Ethics/index.aspx

Please remember to submit a new Self-Assessment Form for each new project.

Click Research Governance for further details regarding the University's Research Governance and Clinical Trials Insurance processes, or email researchgovernance@contacts.bham.ac.uk with any queries relating to research governance.

APPENDIX FOUR – PARTICIPANT INFORMATION SHEET

Introduction…

Hello! My name is Sharon and I am ‘mum’ to a wonderful daughter, who is 15 years old. She has Down syndrome. Since her birth, I have volunteered and worked in a number of roles relating to disabled children and their families. Frustrated with the ongoing difficulties many families face, especially in relation to the education of their children, I decided to return to study to learn more about education, inclusion and how families can work together to improve the lives of disabled children.

I am particularly interested in how we, as parents of disabled children, think about which type of education setting is best for our children and what impacts or influences our decision making. I am now undertaking a PhD study at the University of Birmingham, designed to explore these topics further (further details are below). This study has received ethical approval from the University of Birmingham. The research is being supported by a British Educational Research Association (BERA) Doctoral Fellowship. Therefore, I will also adhere to BERA’s Ethical Guidelines and Code of Conduct.

I would be delighted if you were willing to be involved in my research study. Before you decide whether to agree to take part it is important for you to understand the purpose of the research and what is involved as a participant. Please read the following information sheet (and appendices) carefully and then feel free to ask any questions you may have, for instance if anything I have written is not clear or if you require further information. It is important that you take whatever time you need to decide whether you would like to take part.

If you are willing to take part in this research, please fill in the consent form provided and return it to me by xx/xx/xx. Please retain this information sheet and a copy of the consent form for your own records.

Thank you – Sharon 😊

Participant Information Sheet – [insert date]

Project title: ***Being 'mum' – the subjectivity of parents of children with Special Educational Needs & Disability and its impact on inclusion***

Researcher(s): Sharon Smith
Department: School of Education
Contact details: [redacted]
School of Education, University of Birmingham, Edgbaston, Birmingham B15 2TT

Lead Supervisor name: Professor Julie Allan
Lead Supervisor contact details: [redacted]
School of Education, University of Birmingham, Edgbaston, Birmingham B15 2TT
+44 (0)121 414 4853

What is the research about?

As parents of disabled children, from the time our child is born or diagnosed, we are bombarded with advice and information about how we should parent or educate our children. Some of this is from professionals, some from family members or friends, some from strangers or even the media.

The purpose of this study is to explore how parents of disabled children understand and enact the role they have now found themselves in, how they understand the concept of 'inclusion', and how this impacts on decisions they make about the type of education setting their child will attend (mainstream school, special school etc). Parents frequently are forced to, or choose to, take on particular roles, which are not roles other parents are expected to do. How we decide which roles and decisions are best for ourselves and our families, will be determined by a range of factors and influences. This study is designed to explore these factors and influences, giving parents an opportunity to reflect on decisions that they have taken or might have wanted to take but felt prevented from doing so.

The research has been designed in a way that is not a study 'about' parents of disabled children. Instead, the research will take place with parents of disabled children, to explore topics of interest relating to education and inclusion together, with a view to then documenting the evolving thoughts and conversations that will take place. It is not a conventional study that positions the researcher as someone who collects data about research participants and writes about them. Instead, it is a collaborative project, where ideas and reflections will be explored together, in a way that hopefully provides new ways of thinking about the importance of the role of parents in the inclusion of disabled children.

Why have I been invited to take part?

You are being invited to take part because you are a parent/carer of a child or young person who has Down syndrome (4-18 years old). Although the study has the word 'mum' in the title, it is open to all parents to take part. The use of the word 'mum' is merely being used as a signifier of one of the ways in which parents might find they are related to by others. The study is open to all parents, whatever their gender, and whether they are birth parents or foster/adoptive parents.

What will happen to me if I take part?

If you agree to take part in the study, you will take part in an ongoing 'conversation' with me about your role as a parent of a disabled child and your thoughts on their inclusion in education. This conversation is likely to take place over a period of weeks or months, depending on what free time you have and how much we decide we have to talk about. I have provided more information in Appendix One if you would like to find out more about what this might look like.

How long will my participation last?

Due to the nature of this study, and the nature of conversation, there is no fixed finish date. However, as you are likely to want to have a guideline as to what you are committing to, I think that this is likely to require a commitment of no more than six months in duration. I envisage that we will have between three to six interactions during this time period, all of which could take place face to face, as video/telephone conversations, or by email, depending on your preferences. After each interaction, we will discuss and agree future involvement and together we will decide what the next steps will be. I will not try to persuade you to stay involved any longer than you wish to.

The research study will therefore look different for every parent taking part, and some parents will be involved for longer than others. It is hoped that we will reach a point where we both feel that the engagement has reached its natural conclusion. However, if you feel that you are ready to stop the 'conversation' at any point, we can bring your participation to a close with a final reflection.

Do I have to take part?

No, there is no obligation for you to take part. Participation is completely voluntary. You will be asked to sign the attached consent form to say that you are happy to take part in the research. Before any telephone/video call or meeting, I will also check with you that you are happy to continue to be involved. You can ask to stop your involvement with the research at any point, ie. not have any further correspondence, telephone/video calls or meetings with me.

Will my data be kept confidential?

Yes! All information obtained during the study will be kept strictly confidential. If you provide any photos or videos that identify yourself or your child, I will write a description of these before deleting them from my computer. I will send you a copy of the description, to ensure you are happy with my representation of the item provided and you can make any changes to this if you wish.

See Appendix Two for more information.

Are there any risks to me?

I recognise and understand that talking about our children and family lives can be uncomfortable and/or difficult at times. Therefore, whilst I hope to provide a safe environment, which minimises any discomfort for you, should you feel upset or uncomfortable at any point during our discussions, you have the right to decline to answer any questions, to take a break or to end the conversation. I will remind you of this throughout the research. Additionally, you do not have to share any information or experiences that you do not feel happy about sharing with me. I will not put any pressure on you during the conversations to discuss specific topics if you do not want to.

What will happen to the results?

I will be writing up the research in a report known as thesis, which will be shared with and reviewed by an exam board of the University of Birmingham in 2023 (if all goes to plan!).

I will be working in a variety of ways to make sure that my findings have impact – that they matter and are meaningful and relevant to the lives of disabled children and young people, and their families. I will seek to share what I have found in a number of different ways to ensure that people know about them. This could include conferences, training, and inputting into Government Consultations or Select Committees and publishing in journals amongst other things. No personally identifiable data will be shared.

Can I withdraw from the study?

Yes, you can withdraw at any time, up to three calendar months after our final reflection has been concluded, and you do not have to give a reason. If you decide to stop your engagement or withdraw from the research, we will agree together what, if any, anonymised information about you or your family will be included in the research thesis or future presentations/ publications.

If you ask for complete withdrawal from the study and ask that none of your information is included in the thesis or any other publications/presentations, I will immediately delete all copies of my notes and records. This will ensure that they are not used or referred to, at any point. It should be noted, however, that my own understanding of parents of disabled children and inclusion will be impacted by our conversation. Therefore, whilst I will do my utmost to ensure that your details are not included in the thesis should you decide to completely withdraw, it is important to understand that your influence may still be present in my memory and therefore within the final thesis. It will be impossible for me to return to the position of not having met you or discussed your experiences.

Who do I contact if I have any questions or concerns about this study?

If you have any further questions or concerns about this study, at any time, please speak to me or to my Lead Supervisor at the University of Birmingham: Professor Julie Allan

[redacted]

Appendix One – The Research Study

Like any conversation, it is impossible to plan out in advance exactly where the conversation will take us, or what it might involve. There also might be a number of interruptions or breaks, because life is often messy and unpredictable. However, the conversations in this study are all likely to include some similar stages, which I set out below to give you an idea of what this could look like for you:

- If you agree to take part you will need to sign and return the attached consent form.
- We will then arrange an initial telephone conversation, which will not form part of the research (I will not record this or take any notes). This call will be so that we can

discuss some of the practical aspects of the research and to agree a suitable time and venue for our first meeting (which would ideally be face to face).

- Prior to the first meeting, I would like you to set aside some time to think about your experiences as a parent of a child who has Down syndrome specifically in relation to their education. How you do this will be up to you. How long you take to do this, will also be up to you, as I recognise that your life is busy and you have many demands placed on your time.
- It would be useful if you could bring something to the first meeting to help start our conversation about your role as a parent in relation to your child's education, for instance you could:
    - Choose to write a 'story' or 'history' about your experiences as a parent that you bring with you
    - Choose to bring copies of documents you have written previously about your experiences or about your wishes for your child's education – reports you have written for statutory assessment for an EHCP, diary entries, social media posts, blogs etc.
    - Choose to bring an item or a photo which you feel will be useful to start our conversation
    - Bring something else that you think might be interesting or useful. It really is up to you!
- After we meet, I will type up notes or transcripts of any conversation you have agreed I can record, and I will send them to you to check and to think about. This will include some of my thoughts and reflections too. Both you and I will have time to reflect and think about our conversation before we arrange to converse again.
- The ongoing conversation can take place on the phone, face to face, by video call or email. The frequency of our interactions will depend on when you are available and also when we think it will be suitable to speak next. These conversations might involve you bringing more documents or other items with you, for instance if you wish to use something to support you to think and talk about a specific situation or something else you want to talk about.
- At the end of each conversation we will have time to reflect on the notes/records I provide, and we will agree when and how we will next speak. We will always ensure this fits in with your commitments and time availability. If you think of anything you want to say before our next arranged session, you can email me your thoughts or ask to meet earlier than planned.

I will continually be checking back with you to give you the opportunity to check transcripts (where I type up our conversations into written form for my future reference) are accurate and that you are happy with everything I have written or noted about our engagement. Additionally, the research has been designed to enable you to reflect on our discussions and for your reflections to be included as an important part of the research. If at any time you want something you have previously said or provided to me to be deleted, I will do so immediately.

Most conversations draw to a natural conclusion, and this is likely to happen within this research too. When we agree it is coming to an end, we will have a final discussion and reflection about how our thinking might have changed during the exchange.

After our conversation has finished, I will share the written summary of our reflections and any further thoughts or conclusions with you, in case you wish to:

- ask for some information to be withheld
- ask for something to be changed
- think of something else you think should be included.

You do not have to provide feedback though; it will be completely up to you. Additionally, you can still change your mind about being involved in the research and you can ask to 'withdraw' from the study. This would mean that you were no longer involved, and that, as much as possible, your information will not be included within any written or oral outputs following the research.

Appendix Two – Confidentiality and data storage

If any information about you or your family is published or discussed it will be entirely anonymous. You and your family will not be identifiable. To enable this, you will be given an alias/pseudonym, which I will use to refer to you in all of my own notes and files, instead of using your real name. You can choose your own pseudonym if you would like to. You can also waive your right to anonymity and choose to use your real name if you wish.

The study will form the basis for my PhD thesis, which I hope to share in journal publications and conference presentations. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access, which means that it is open to the public. Your pseudonym will, of course, be used at all times to ensure your identity is kept completely confidential.

Any information you provide to me will be stored anonymously using your pseudonym, which is not traceable back to you. Myself and my Doctoral supervisory team at the University of Birmingham (Professor Julie Allan and Dr Clara Joergensen) are the only people who will have access to the information you provide as part of this research. I will need to share the data with them during my monthly supervision meetings during the development and writing of my thesis. My supervisors will, however, only have access to information that has already been anonymised.

All digital files associated with the study will be kept within password protected folders that are stored using your pseudonym and which will contain no identifiable information. However, I will have to keep a separate password protected document that links the pseudonyms to the participants' initials, in order to identify your data in case you decide to withdraw in the future. This document will be only accessible by me and will be destroyed at the end of the research project.

At the end of the project, anonymised data may be archived and might be shared with others for legitimate research purposes. Your identity will continue to be protected and will not be provided to other researchers. All research data and records needed to validate the research findings will need to be stored for 10 years after the end of the project, again these will use the pseudonym and not your real name.

Please note: confidentiality may have to be breached in the unlikely event of concerns arising about the safety of any individual or if a safeguarding issue arises.

APPENDIX FIVE – COMMITMENT/CONSENT FORM

Participant Consent Form: ***Being 'mum' – the subjectivity of parents of children with Special Educational Needs & Disability and its impact on inclusion***

Researcher(s): Sharon Smith
School of Education, University of Birmingham, Edgbaston, Birmingham B15 2TT
Contact details: [redacted]

Lead Supervisor name: Professor Julie Allan
Lead Supervisor contact details: [redacted] [redacted]

I need you to confirm that you understand the purposes of the research project and what it will involve. It is important that you ask me any questions you may have, to ensure you are happy to be involved before you sign this form. However, before you provide your consent, I want to outline my commitment to you.

- **I will approach you and your family fairly and sensitively** – I will not treat you differently because of your age, gender, sexuality, ethnicity, class, nationality, cultural identity, partnership status, faith, disability, political belief or any other significant characteristic. I will respect your rights.
- **I will keep your identity private** – I will ensure that I am the only person who knows your identity, using an alias on all stored records and redacting any personal information. You will be able to choose a pseudonym, an alternative name, which is how your information will be stored and referred to, unless you want to use your own name. Please note that confidentiality may have to be breached in the unlikely event of concerns arising about the safety of any individual or if a safeguarding issue arises.
- **I will keep your information safe** – I have written a data management plan, approved by my Supervisor, which outlines how I will keep all of your information safe. This plan is in line with University of Birmingham data management guidelines. Your personal data will be processed only for research purposes, as explained in the information sheet.
- **I will not put any pressure on you** – your involvement is voluntary and you can end the conversation or choose to withdraw from the research at any point. Meetings and any agreed telephone/video conversations will be arranged for a time and location that suits you. I will check with you on the day to ensure that it is still convenient, as I know how life with a disabled child can sometimes throw curveballs your way! The conversation will fit in with your life, rather than my requirements as a researcher.

- **I will support you** – I will ensure that the research is undertaken in a supportive way. If you feel uncomfortable in any way during the research engagement, you can choose not to answer any question, to take a break or to end the conversation. Additionally, prior to the study, I will collate a list of support organisations and websites, that might be of use to any parents taking part in the study, which I can share with you at any time on request.
- **I will ensure you are happy with how you are represented or discussed in the research outputs –** the research has been designed as a ‘conversation’ to ensure that you are fully involved in all aspects of the research, including discussions about how you and your experiences are presented in any written or oral reports.
- **I commit to using this research to explore new ways of thinking -** I am not going into this study with any pre-conceived ideas about what the study should or will find out about parents, disabled children, or inclusion in education. However, I am driven by a desire to find new ways of thinking about the role of parents in relation to the inclusion of disabled children. I hope to achieve this by engaging with other parents of disabled children in a conversation about their experiences, what has influenced their thinking, and how things could potentially be done or thought about differently, in order to improve the inclusion of disabled children in education. I commit to sharing the findings of the research in wide and varied ways.

Your consent:

- I confirm that I have read and understand the participant information leaflet for this study dated dd/mm/yy. I have had the opportunity to ask questions if necessary and have had these answered satisfactorily.
- I understand that my words may be quoted in publications, reports, and other research outputs, but that no identifiable personal data will be published.
- I understand that I will not benefit directly from participating in this research and will not receive any payment for my time.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. If I withdraw my data will be removed from the study and will be destroyed unless I agree otherwise in writing.
- I understand how my personal data will be processed and stored.
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities. They will discuss this with me first but may be required to report with or without my permission.

Based upon the above, I agree to take part in this study.

__________________ __________________ __________________

Name of the participant Signature Date

Sharon Smith

__________________ __________________ ___________________

Name Signature Date

APPENDIX SIX – DATA MANAGEMENT PLAN

Being ‘mum’ - the subjectivity of parents of children with Special Educational Needs and Disabilities and its impact on inclusion

Data description

What types of data will be used or created?

Due to the proposed postqualitative methodology, it is hard to ascertain exactly what data will be obtained or created in advance.

The research might generate (but is not limited to) the following:

- audio or video recordings eg from interviews or discussions with participants either face to face or online. This could consist of

recordings taken on my telephone or an audio recording device (both of which will be used to record discussions with participants to

ensure a back up copy should one device fail) or Zoom recordings of webchat discussions

- typed transcripts from interviews/engagement with participants

- researcher’s records of observations, summaries after engagement, reflections eg emotions/feelings or how the data links to theory

or specific topics related to the research, notes summarising telephone conversations etc.

- participants might provide copies of photos, letters, reports, social media posts/blogs, entries from personal diaries or other visual/written material

- participants will be invited to provide comments or feedback on the researcher’s observations or analysis, which could be in verbal or written form

The data will be generated over a sustained period of engagement with no more than ten research participants. Each participant’s file is likely to generate different types of data, depending on how the research progresses.

How will the data be structured and documented?

All participant data will be anonymised and will be allocated a pseudonym as soon as they agree to take part in the research.

Participants can choose their own pseudonym if they wish.

Each research participants will have their own folder, in which all information relating to them will be stored. This will be named

using their pseudonym rather than their actual name. All files will use the following structure <pseudonym /date/information type> (for instance Sharon210320email.pdf).

Data storage and archiving

How will your data be stored and backed up?

I will store the following documents as follows:

- scanned copies of any handwritten notes from my own thoughts/observations/reflections relating to engagement with participants

- any photographs/written material provided to me by participants

- all typed notes/observations/reflections relating to engagement with participants

- typed up copies of transcripts of recorded interviews or discussions with participants

- copies of email correspondence sent to or by participants

- all original audio and video files will be uploaded electronically to the 'Personal Vault' on Microsoft OneDrive (a cloud based system) which is encrypted and then secured by two-step verification and an auto lock after three minutes of inactivity.

Back-up copies of all files will be stored in two further places:

- On the University of Birmingham OneDrive

- On University of Birmingham BEAR storage (the university's Data Store)

I will update and back up files daily during the period in which I am undertaking empirical research and throughout any subsequent analysis.

Is any of the data of (ethically or commercially) sensitive nature? If so, how do you ensure the data are protected accordingly?

My research relates to human subjects (parents of disabled children) and is therefore sensitive personal data.

All participants will provide written signed consent prior to commencement of the research, in which they consent to their data being stored and shared in research dissemination (conferences, papers, book chapters for example). They can withdraw from the study at any time and can ask for their data to be deleted.

All participant data will be anonymised and will be allocated a pseudonym as soon as they agree to take part in the research.

Participants can choose their own pseudonym if they wish.

Each research participants will have their own folder, in which all information relating to them will be stored. This will be named using their pseudonym rather than their real name.

All files will use the following structure <pseudonym /date/information type> (for instance Sharon210320email.pdf)

If participants choose to provide me with copies of any documentation that includes any identifying information, I will scan these in/save electronically and will redact all identifying information on my saved versions. Original copies will be returned to the participant or if they are photocopies that do not need returning, they will be shredded using a secure data collection service.

I will only use University of Birmingham email for corresponding with participants. This is stored in the cloud and is password protected. I will delete all emails once I have saved a PDF version in the participants' data file as detailed previously.

Where will your data be archived in the long term?

Anonymised data will be stored on University of Birmingham's Research Data Archive for 10 years. Once transferred the data will be set to read-only to prevent any inadvertent additions or deletions of the dataset. Any changes will result in a new dataset, which will be archived separately. Data will be stored for 10 years, should access to the data be requested within a 10 year period, the 10 year clock is then reset from the point of last access. After the 10 year period the data will be deleted.

Data sharing

Which data will you share, and under which conditions? How will you make the data available to others?

The data will be used for writing my PhD thesis. Additionally it will be shared in research dissemination activities such as presentations or written papers/chapters. Pseudonyms will be used in all instances. Participants will be required to provide written consent for this at the outset of the research. If they do not wish their data to be shared further at any point they can withdraw this consent and their data will not be used in any further oral or written presentations.

I will only share anonymised data in other instances, eg if I receive a request to do so, by obtaining explicit participant permission for the particular situation. Otherwise, the data will not be shared with a wider audience. This research is not funded by a research body and therefore there is no expectation or requirement that the data will be made more widely available after a period of time

APPENDIX SEVEN – EMAIL TO GATEKEEPERS

Dear [insert name]

I am a PhD research student at the University of Birmingham, undertaking a study relating to parents of disabled children and the inclusion of their children within education. As part of my research, I am hoping to recruit between 5 and 10 parents of children with Down syndrome in England to take part in a conversation with me about their views on inclusion and their experiences as a parent. The attached information sheet provides more information.

I would be incredibly grateful if you might be willing to share my request and the attached information with any parents of children with Down syndrome (4-18yrs old) known to your organisation/school. I am keen to ensure that participants' identities are kept anonymous in the study, so I am contacting a number of organisations and schools to recruit participants.

I myself am a parent a wonderful daughter who has Down syndrome. Since her birth, I have volunteered and worked in a number of roles relating to disabled children and their families. I will therefore handle all interactions with the families you know sensitively. I also plan to prepare an information sheet with local support information on, should parents taking part in the study indicate that they need signposting to any local support organisations.

This study has received ethical approval from the University of Birmingham. The research is being supported by a British Educational Research Association (BERA) Doctoral Fellowship. Therefore, I will also adhere to BERA's Ethical Guidelines and Code of Conduct throughout this study. If you require any additional information before you share details of this research with families you know, I would be more than happy to answer any questions you may have. Alternatively, you are welcome to contact my supervisor Professor Julie Allan at the University of Birmingham. Professor Allan's contact details are on the attached information sheet.

Any parents who are willing to take part in this research, will need to fill in the consent form provided and return it to me by 30 June 2021.

Please accept my thanks in anticipation of your support of my research study.

With very kind regards,

Sharon Smith

PhD research student

School of Education, University of Birmingham

[redacted]

APPENDIX EIGHT – PROMPT SHEET FOR TELEPHONE CALL

1. Purpose of phone call / set out what we will discuss

2. Ask for permission to take handwritten notes which I can share afterwards if they would like

to see them

3. Before we start – any questions?

4. Introduce self

    a. Parent of 16yr old who went to mainstream, starting college in September

    b. Started down syndrome support group with Emma when she was 18m, joined

    parent carer forum 2011-2014, continue to work with families via work with

    Contact, started degree in 2014 then did MA now doing PhD

    c. Interested in using philosophical approaches to education to think about inclusion differently

5. Ask them to introduce themselves

6. Introduce research – go through the info sheet

    a. What is it about?

    b. What will it look like in practice - options

7. Any questions?

8. Confirm still want to be involved

9. Agree next steps

    a. What would they like the first 'meeting' to look like – face to face, video call, email?

    b. What they need to do before we start the conversation

    c. Timescales

    d. pseudonym

APPENDIX NINE – TEMPLATE FOR SUPPORT DOCUMENT

Sources of support and information – collated by Sharon Smith (University of Birmingham)

Contact – the charity for families of disabled children

www.contact.org.uk

Information/advice/support about education, health, social care, post 16, benefits, grants, sleep, behaviour andmore. They offer a free helpline 0808 808 3555 and a 'Listening Ear' Service where you can call and speak to someone for support or information https://contact.org.uk/help-for-families/information-advice-services/get-intouch/talk-to-us/listening-ear.

The Down's Syndrome Association (DSA)

https://www.downs-syndrome.org.uk

They offer a free helpline 0333 1212 300 (10AM-4PM) HELPLINE@DOWNS-SYNDROME.ORG.UK

The Down's Syndrome Association supports people who have Down's syndrome, and their parents and carers, throughout their lives. From before birth into older age, the DSA provides services to everyone.

IPSEA

https://www.ipsea.org.uk

IPSEA offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). They also provide training on the SEND legal framework to parents and carers, professionals and other organisations.

SOS!SEN

https://www.sossen.org.uk 0300 302 3731 or 0208 538 3731

SOS!SEN offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs and Disability (SEND). They also run walk-in advice centres.

Cerebra

https://cerebra.org.uk Email: enquiries@cerebra.org.uk Helpline (freephone): 0800 328 1159

Cerebra are a national charity dedicated to helping children with brain conditions and their families discover a better life together (includes Down syndrome). Their aim is to provide the best research-driven, high-quality health, legal, financial and social care advice for children with brain conditions and their families. They offer a Legal Rights Service to provide families with help when facing difficulties accessing support services they are entitled to.

Down Syndrome Education International (DSEI)

https://www.dseinternational.org/en-gb

An international charity that supports scientific research and delivers evidence-based advice and information to improve outcomes for children with Down syndrome worldwide.

Council for Disabled Children (CDC)

https://councilfordisabledchildren.org.uk/resources-and-help/im-parent

CDC have an online library of resources that you can access to find out more about disability policy and practice which includes a selection of materials specifically written with parents in mind.

Family Fund

https://www.familyfund.org.uk

Family Fund is the UK's largest charity providing grants for disabled children and their families.

Special Needs Jungle

https://www.specialneedsjungle.com/

Special Needs Jungle provides parent-centred information, news, special needs resources and informed opinion about SEND.

Local Offer

[insert link]

A Local Offer gives children and young people with special educational needs or disabilities and their families information about what support services the local authority think will be available in their local area.

SENDIASS (SEND Information, Advice and Support Service)

[insert link]

The Special Educational Needs and Disabilities Information Advice and Support Services offer information, advice and support for parents and carers of children and young people with special educational needs and disabilities (SEND). This service is also offered directly to young people.

Parent Carer Forum

[insert link]

A parent carer forum is a group made up of parents and carers of disabled children who work with local authorities, education, health services and other providers to make sure the services they plan and deliver really meet the needs of disabled children and families. The forum represents the views of parents in the local area but does not advocate for individual families.

Local support groups:

[insert links]